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# "We are not aliens": Exploring the Meaning of Disability and the Nature of Belongingness in a Fourth Grade Classroom

**Priya Lalvani Zola**

**Abstract** *In this narrative essay I describe the process and outcomes of a group of fourth graders' engagement in a critical inquiry into the constructed meaning of disability in society. Through self-directed and guided learning, these students examined the historical roots of disability oppression and deconstructed ableist assumptions, and thus found their own understanding about community membership to be transformed. Positioning the need to infuse disability history in schools as an imperative, this paper invites disability studies scholars and social justice educators alike to confront the silences around the topic of disability in schools and to create spaces for children to engage in meaningful dialogues about society's responses to human differences*

**Keywords:** *social justice education, disability history, ableism, inclusion, disability, critical pedagogy*
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## Introduction

At the outset of this essay, I wish to locate myself and my relationship to the work I describe herein. I am, among many other things, a disability studies scholar, a teacher educator, and a mother; my frames of reference are situated within these identities, my agendas driven by the tasks I associate with these roles. As a disability studies scholar, I endeavor to examine cultural and institutional master narratives on families of children with disabilities, which derive from, and uphold, the constructed meaning of disability in society. As a teacher educator whose work is grounded in the traditions of transformative social justice pedagogies, I strive to prepare inclusive teachers who will instill in their own students an appreciation for human diversity and who are able to recognize and disrupt problematic discourses and practices pertaining to students with disabilities in schools. As a

mother, I grapple with how I might nurture in my two children — one who has a disability and one who is culturally understood as nondisabled — a positive identity, a sense of self-worth, and an ethic of caring and social consciousness, within the context of an ableist society which positions disability as a predominantly negative phenomenon, families like mine as non-normative, and children with disabilities as "other."

Campbell (2001; 2009) explicates the concept of ableism as the persistent devaluing of disability or as viewpoints in which disability is cast as an inherently negative state of being. Ableism operates as a "pervasive system of discrimination and exclusion that oppresses people who have mental, emotional, and physical disabilities" (Rauscher & McClintock, 1996, p. 198). Dominant cultural narratives are deeply entrenched in ableism, and perhaps nowhere is this more evident than in the master narratives on normative motherhood and desired children that surround the birth of a child with a disability. My own awareness of ableism became heightened when my daughter was born — and shortly after found to have an extra chromosome on her 21st pair. I found myself bombarded with implicit and explicit messages about disability as a predominantly negative phenomenon. In interpersonal and institutional discourses, cultural definitions of children with Down syndrome as undesirable ("Why didn't you just have an amniocentesis?"), beliefs about families of children with disabilities as burdened ("God only gives special children to those who can handle it"), and notions about the experience of raising a child with Down syndrome as outside the parameters of normative motherhood ("You must have the strength of a saint") were upheld. A more subtle form of ableism manifested itself in the comments of some well-meaning friends and acquaintances who assured me that, at least at first glance, "nobody could tell" that my daughter had Down syndrome. I was, and I continue to be, intrigued by the idea that in the cultural environment within which I exist, it is generally taken to be an unquestioned good that a baby who has Down syndrome might "pass" for one without.

Later, I encountered a somewhat different form of the discourse of "passing" — this time in the context of inclusive schooling. In numerous conversations with my daughter's elementary school teachers over the years, when I have inquired about how they might introduce or discuss the topic of disability in the classroom, or how they answer questions from classmates about my daughter's differences, I have generally been assured that her classmates "don't notice anything different" or that "she blends right in, so nobody can tell." I am skeptical about these claims. Do young children actually not notice differences in the ways in which some of their peers communicate, learn, or move around? Are they not curious about the adaptive devices, the modified classwork, the occasional removal from the classroom of some students, or the presence of professionals delivering specialized services to some others? Should their lack of questioning be taken as indication that they are not curious about differences, or might this perhaps signal that they have learned to silence their curiosity about certain kinds of differences?

It is these silences around the full range of human variation and these unquestioned assumptions about the inherent goodness of the invisibility of disability with which I am concerned. I view these through the lens of ableist ideologies in schools and society. In his seminal studies on intergroup prejudice, Allport (1979) explicated that physical proximity alone is not enough to reduce intergroup prejudice; rather, prejudice reduction is most likely to occur when members of different groups are positioned as having equal status and are institutionally supported to collaborate with each other in pursuit of common goals. Therefore, problematizing the absence of conversations around disability in schools, I

question whether nondisabled children who sit alongside a child with a disability in an inclusive classroom can gain either any meaningful understanding of disability or any genuine appreciation for the diversity within their school community if there are silences around the questions they surely must have. Additionally I question how children with disabilities, such as my daughter, can develop a positive sense of self if one aspect of their experience — or one facet of their identity — is never acknowledged or named? These are the questions with which I grapple daily and which provided the impetus for the project I discuss in this essay.

Disabled people have a collective story — one that is situated in institutionalized ableism and in which they have been often denied access to their most basic civil rights. As Davis (2006a) states, people with disabilities have been isolated, incarcerated, mistreated and controlled to a degree unequal to that experienced by any other group. Although the collective history of the disabled is an account of oppression, it is also an account of radical action, empowerment, and the evolution of disability pride and identity. Like members of other historically oppressed groups, disability rights activists have forged a civil rights movement aimed at challenging the marginalization of people with disabilities and positioning them as part of the mainstream of society (Connor & Gabel, 2010).

In recent decades, there have been drastic changes in the ways in which people with disabilities in the US have been understood and treated, in no small part as a result of the efforts of disability rights activists and the emergence of the disability civil rights movement. Yet, the story of disabled people in America has generally remained outside of the public awareness and "in the locked wards of academic inquiry" (Burch & Sutherland, 2006, p. 127). Race, class, and gender have been the dominant lenses for studying social history in the US since the 1950s and the conspicuous impact of this can be seen in American history textbooks; today it is inconceivable (and rightfully so) to teach American history without including the important role and collective histories of ethnic minorities, the working class, or women (Burch & Sutherland, 2006). However, American history textbooks do not include disability in a meaningful way, rendering it inaccessible (Burch & Sutherland, 2006); indeed, the vast majority of high school graduates in the US are unlikely to have any knowledge of disability history nor any awareness of the existence of the disability rights movement, as typically there is little or no mention of these in k-12 curricula. Alarmingly, like their students, teachers too seem to have little or no knowledge about these topics. To wit, each semester when I ask my graduate students — most of whom are in-service teachers working toward their TSD (Teacher of Students with Disabilities) certification — to share their thoughts on teaching disability history in k-12 classrooms, the overwhelming majority state that they have not heard of such a thing ("Disability rights movement? What's that?"). Ironically, on more than one occasion, my students have mistakenly understood my question to be a query about teaching history to students with disabilities, rather than teaching about disability history. This represents a missed opportunity and a loss at many levels. For one, as Sarason (1999) asserts, every professional should have knowledge of the history of their field "because without such knowledge one's own sense of professional identity is an impoverished one" (p. xviii). Additionally, as Kudlick (2003) states, in k-12 education, disability is a topic worth studying in its own right; not only does it provide a more nuanced picture of power and oppression in our country, but it simultaneously allows students to explore complex issues of what it means to be human, who gets to decide, and how we, as a society respond ethically to human differences.

The reduction of prejudice and discrimination is an identified objective of progressive multicultural education (e.g., Banks & Banks, 2012; Nieto, 2000); many social justice scholars have asserted that multicultural education needs to question the domination of some groups by others and to address issues pertaining to injustice head-on through critical pedagogy — also called transformative or emancipatory pedagogy (e.g., Apple, 1996; Giroux, 1991; Nieto, 1999; Sleeter & Grant, 1993). Progressive educators have responded to this need by infusing anti-bias (e.g., anti-racist, anti-sexist, etc.) curricula in schools. However, there is a glaring omission of the topic of disability oppression from critical multicultural education (Lalvani & Broderick, 2015), and in conversations on social justice, disability has "traditionally been turned away from the table" (Connor & Gabel, 2010, p. 202). As Hamre, Oyler, and Bejoian (2006) state, even in the "progressive spaces where commitments to social justice are real and enduring, the lives and experiences of people with disabilities are sometimes overlooked" (p. 91). Perhaps this is because disability continues to be regarded through the lens of deficit; despite having come a long way in our understanding of disability, even today, society and the academy alike rely on a medical model paradigm in which disability is "cast as a diminished state of being human" (Campbell, 2001, p. 44), rather than as naturally occurring form of human diversity.

In contrast, the social model of disability (Oliver, 1990) rejects the notion that people with disabilities are inherently "defective" and solely in need of rehabilitation, positioning them instead as a marginalized minority group. Disability studies scholarship, grounded in the social model, is concerned with the socio-political constructions of disability and normalcy; as such, it is less interested in human differences per se, and more interested in what society makes of these differences (Davis, 2006b; Linton, 1998). Framed in these perspectives, in recent years there has been a growing push for the positioning of the topic of disability oppression and ableism under the conceptual umbrellas of multicultural education and social justice education (e.g., Connor, 2012; Ware, 2006). These scholars argue that if social justice education aims to prepare future citizens to effect change in society, then we need to problematize the general omission of the topic of disability from the "social justice inventory" (Slee, 2001, p. 174).

**"They Don't Even Notice" Discourses on Children's Understanding of Disability and Difference in Schools**

A pervasive master narrative in schools today pertains to the notion that young children "don't notice differences" among themselves. As noted earlier, over the years whenever I have asked elementary school teachers about how they might explain my daughter's differences to classmates who express curiosity, or about how they discuss disability as human variations in the classroom, I have typically received response such as: "We don't need to say anything — they don't even notice she's different" or "They don't ask any questions — children are so accepting." Similarly, it is not uncommon for a teacher to claim that he/she treats "each student the same," or that a visitor to their classroom would be "unable to tell which child has a disability."

In dominant educational discourses steeped in ableist assumptions about the negative nature of disability, not noticing disability seems to be understood as an unquestioned good. This is resonant of the "colorblind ideology" in schools, i.e. teachers' beliefs that they do not notice children's race (Schofield, 2004). Critical educators discuss colorblind ideology as antithetical to fairness and tantamount to racism (Bonilla-Silva, 2003; Choi 2008). As Gordon (2005) writes: "Colorblindness is a bid for innocence, an attempt to escape our

responsibility for our White privilege. By claiming innocence, we reconcile ourselves to racial irresponsibility" (p. 143). Highlighting that there is often a silence around racialized conversations, social justice educators have called for more open dialogue on race in schools. In response, many teacher education programs have introduced Critical Race Theory and Critical White Studies in an effort to prepare teachers to be able to develop curriculum and pedagogy in relation to institutional racism (Choi, 2008). Posing a paradigmatic challenge to colorblind ideology, critical multicultural education positions the conversation on race at the forefront in any analysis of social relations (e.g. King, 1991; Sleeter, 1996; Tatum, 1997).

Less critiqued however, are educational ideologies in which fairness is interpreted as equal treatment, and claims about not noticing disability are positioned as unbiased ways of relating to students. Dominant narratives entrenched in these ideologies have hitherto remained largely unchallenged and consequently there are few meaningful conversations about disability in schools. Ware (2001) asserts that many teachers, even those who genuinely strive toward inclusivity, feel concerned, fearful, or ill-equipped to take on discussions about disability within their curricula, believing that someone else would know more about this topic. When disability is left unmentioned in the classroom, it sends an implicit message to students that this topic has little relevance to them, and furthermore, reifies the notion that disability oppression does not exist. Therefore, there is an urgent need for educators to engage children in deconstructing hegemonic notions about disability and in exploring alternative narratives through critical pedagogies (Ware, 2005). To this end, presenting disability through a cultural lens is imperative. As Connor and Gabel (2010) argue, when teachers actively position disability as a form of diversity, they will be able to teach their students to embrace differences without stigmatizing it, to confront ableism, and to recognize disability as a natural and inevitably occurring difference.

**"Play! Don't Stay Away": A Critical Inquiry Project in a Fourth Grade Classroom**

With regard to the persistence of negative assumptions about disability, Ware (2001) asks: "dare we do disability studies" in schools(p. 107)? Others have similarly called for the infusion of disability studies in k-12 curricula and the use of critical pedagogies aimed at teaching children to recognize and disrupt ableism (e.g., Connor & Gabel, 2010). Consistent with these ideas and based on a belief that issues related to group prejudice can be explored at any grade level, I developed a curriculum for a critical inquiry on the topic of disability, in/exclusion, and ableism which I implemented (as a pilot) with a small group of students in my daughter's fourth-grade classroom. In this essay, I discuss the process and outcomes of these students' engagement in the project — which in due course obtained the student generated title of "Play! Don't Stay Away" — in which we collaboratively endeavored to explore the constructed meaning of disability and our own negotiated identities within this construction, and to understand the nature of inclusion/exclusion, community belongingness, and social change.

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Endnotes

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# The phenomena of interference of perceptive character in conditions of artificial bilingualism

**Malahat Akbar Veliyeva**

**Abstract**

*The aims and objectives of the article are to observe the I nterference phenomena of perceptive character occurring in bilinguals' speech and to find out its reasons and the ways of improving such language deficiencies.*

*By means of direct observation and interview methods bilingual individuals' mistakes in the oral and written English caused by the interlanguage and intralanguage phenomena of interference of the perceptive character were revealed. The key finding of the research of the interference of perceptive character is that wrong perception or absence of the foreign utterance perception interferes the process of communication and transmission of thoughts, inf ormation.*

*The innovation of the research is first of all different approach to the study of bilingualism that is bilingualism in artificial, auditorium conditions.*

*The theoretical value of the research is the perspectives of being used in the study of interference at other levels of the language apart from morphemic level. It can be useful for future research of the interference phenomena as well as from the point of view of methods of teaching English providing English teachers with theoretical data to be considered in teaching English to Azerbaijani students in conditions of artificial bilingualism.*

**Keywords:** *Bilingualism, bilingual individuals, interference of perceptive character, artificial bilingualism, morphemic interference.*

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## Introduction

Every language has its own system in terms of pronunciation, morphology, lexis, syntax and stylistics. Once individuals, at least bilingual individuals get into a foreign

language environment, specific psychological changes related to cognitive processes which are explained by psychological factors, take place in their language consciousness and in most cases result in interference phenomena caused by divergences between the language structures of the mother tongue and the target language. The interference phenomena might occur at different language levels, such as phonetic, morphemic, lexical, syntactical levels of the language. The phenomena of interference at the morphemic level of the language are in the spotlight of our research. We are making an attempt to study the phenomena of interference of perceptive character in conditions of artificial bilingualism.

Materials and methods

In our research we used direct observation and interview methods which give an opportunity to have a closer contact with the bilinguals who were being experimented and reveal their mistakes in the oral and written English caused by the interlanguage (divergences between the morphological system of the Azerbaijani and English languages) and intralanguage (confusion of the rules and language patterns within the English language) phenomena of interference of the perceptive character. The experiment was done with the Azerbaijani students of the Education faculty of Azerbaijan University of Languages whose level of academic knowledge of English varied from Pre-Intermediate to Advanced levels, in correlation with the Common European Framework. The English level of the first year students coincided with Pre-Intermediate level, the second year – Intermediate, the third year – Upper-Intermediate and the fourth year – Advanced level associatively.

The method of interview, particularly one to one interview was helpful to investigate the Azerbaijani students' mistakes while using oral English and the deviations from the norm caused by the interference phenomena in bilinguals' speech. To check interference phenomena in students' written speech, we used essay writing task and the variety of grammatical activities considering students' potential mistakes caused by the interference phenomena.

About 120 students of Azerbaijan University of Languages with different levels of English participated in our experiment.

Discussion

As per Peter Trudgill (2001), individuals' view of the world may be determined by their native language. So, native language is the basis, the foundation in the individuals' language consciousness which immensely affects the second language acquisition either positively or negatively depending on the degree of the kinship between the contacting languages. In case, the languages in contact are kindred languages, the perception of the target language is by far easier rather than in case of contacting languages having no genealogical kinship. For instance, an Azerbaijani student makes much less effort in learning Turkish or Uzbek languages rather than English or French. It is due to similarities and differences in the phonological, grammatical, lexical, syntactic structures of the languages in contact. Besides this fact, psychological aspect of learning a foreign language is of not less importance. Bilinguals, particularly in our study area, Azerbaijani bilinguals whose second language is English, encounter serious psychological complications in the perception of the English language which hardly has any coincidences with the Azerbaijani language in terms of the language structures.

Research done in the field of the first and second language acquisition proves that language learning is affected by internal and external factors of the learning process (Olguin

K., Katiuska Vega Labra V., 2014, 11). According to P.H. Mathews (2003), the adults' speech changes depending on the environment where individuals use the language. From this point of view bilingualism in natural and artificial conditions differ from each other. In our research we focus on bilingualism in artificial conditions, that is bilingualism in education, in the learning process. Although we investigated bilingualism among Azerbaijani students who are in the process of learning English, we can refer them to bilingual individuals since they can communicate and express themselves in English with more or less academic language competence. In our view students with relative command of English though not completely accurate in the target language can be considered bilingual individuals as it is hard to believe that bilinguals mastering the second language perfectly and impeccably, exist in reality. In that case students, at least those who study the English language for professional purposes (for instance, students of Education faculty of Azerbaijan University of Languages whose future career is teaching English professionally) purport to have the status of bilingual individuals.

Learning the second language implies both positive and negative effects on bilingual individuals' language consciousness. The positive effect of the second language acquisition on learners is the impact on their mental abilities that makes them more confident and satisfied with acquired skills of the new language. However, the second language acquisition entails such negative effect as the phenomena of interference at different language levels which is reflected in bilinguals' deviations from the norms while speaking the foreign language.

Interference of perceptive character is directly related to psychological aspect of bilingualism which implies the Azerbaijani students' challenges with perception of the English language.

At Azerbaijan University of Languages, where the study of foreign languages (in our concrete case, the study of English) is realized in conditions of artificial bilingualism, from the initial stage of their study, students find out themselves in language environment at lectures and seminars in such major subjects as: Phonetics, Grammar, Practice of English and others. Teaching of the above-mentioned subjects is implemented directly in the English language that is extremely complicated for the students without preliminary experience of oral speech communication. In such cases while communicating in English the mother tongue in which students realize their thinking abilities that in many respects helps to translate thoughts from the native into the foreign language. Such kind of communication continues until the time when students master the language to the extent of thinking in it.

Surprisingly at the University of Oslo, Birgite Brok-Witney as a result of research dedicated to the role of education in the sphere of higher education in Africa, came to the conclusion that it is easier for learners to acquire foreign language skills if they are given instructions in their mother tongue even at higher levels of learning the language with the purpose of preserving their national culture and identity (Mother tongue and Bilingual Education., 2008). The author encourages teachers not to ignore the learners' national belonging and culture, also while teaching them a foreign language, to attach equal importance to their mother tongue. This significant factor should definitely be taken into consideration while studying the issues of the second language acquisition. As for the instructions, they can be given in learners' mother tongue in case it will not cause interference phenomena if not in bilinguals' speech, but in their consciousness.

While learning a foreign language in conditions of artificial bilingualism, mother tongue is completely ignored as in most cases classroom conditions are the only language atmosphere for learners. The majority of them are deprived of foreign language atmosphere and the opportunity of lively communication outside the English lesson.

Attending different kinds of conversation clubs, interactive games in English, everyday communication outside the lesson, participation in variety of international events where bilingual individuals feel more relaxed and independent from psychological point of view in comparison with learning environment, in many respects promote to improvement of bilinguals' speech skills as for comprehensive language learning, only learning environment does not always give a desirable effect.

The interference of perceptive character implies wrong perception or the absence of the foreign utterance perception that interferes the process of communication and transmission of thoughts, information.

Azerbaijani students do not face with peculiar challenges related to understanding of phonemes similar to their native Azerbaijani language in auditory perception. The phonemes which are unique and characteristic only to English and do not have the equivalent or similar variant in Azerbaijani language create problems in reproduction, particularly Azerbaijani students' pronunciation of the English speech.

According to linguistic research the distinctive features of phonemes are not enough for perception of the foreign speech, to achieve this connection of the information in syllables is more important than in discrete units (phonemes).

If we approach this issue from the morphemic point of view, we can observe the similar phenomenon when bilinguals after the perception of the English speech in the given tasks make mistakes in morphemes either identifying them with the morphemes in the native Azerbaijani language or use the incorrect forms applying English grammar rules in the wrong situations.

For instance, in our experiment the Azerbaijani students were offered to listen to the authentic audio material in order to observe the phenomenon of morphemic interference of perceptive character in their speech that is from the point of view of their perception of the foreign speech by listening. The audio material was voiced by the British, native speakers of English. After listening the Azerbaijani students were offered the following tasks:

to convey the main idea of the listened material briefly;

to fill in the gaps with prepositions in the sentences where necessary;

The experiment was conducted in three groups:

with Upper-Intermediate and Advanced levels;

Intermediate level;

Pre-Intermediate level with participation of the first, second, third, fourth year students.

50% of the students coped with the given tasks successfully, 30% of the experimented students partially completed the task, in transmission of the main idea of the audio material they used incorrect verb forms, making interference mistakes in tense forms, in plural forms of nouns and in the usage of prepositions which do not have direct parallels in the Azerbaijani language, while 20% of the students absolutely failed to do the task.

The results of the conducted experiment are demonstrated in the below table:

Table 1

| Groups of students where the experiment was conducted | Successfully coped with the task | Partially coped with the task | Absolutely failed to do the task |
|---|---|---|---|
| Upper-Intermediate advanced, intermediate , pre-intermediate levels | 50% | 30% | 20% |

It is not doubtful that this significant role in our experiment belongs to the students' level of English. The first group of students half of which coped with the given task successfully consisted of Upper-Intermediate and Advanced level students, the second group, partially coped with the task belonged to intermediate level, the third group of the experimented participants, half of which made interference mistakes at the morphemic level were first year students with pre-intermediate level of English.

Evidently, half of the experimented students coped with the task having demonstrated effective listening skills. The students who partially completed the task and 20% of the students who absolutely failed to do the task need additional practice of the listening materials voiced exclusively by native speakers of English; they also need verbal explanations of the potential interference phenomena and additional practice in doing exercises for preventing occurring mistakes.

Based on comparative- typological research of Azerbaijani and English languages Azerbaijanian linguists D.Yunusov and L.Khanbutayeva (2008, 209) analyzed the mistakes made by Azerbaijani students while studying English and subdivided them into two groups:

occasional mistakes occurring to incomplete elaboration of the current and covered material which does not have a fundamental character and which are possible to eliminate applying special methodology and additional exercises;

frequently occured mistakes typical of the majority of biligual individuals.

A foreign language teacher's awareness of reasons and prime causes of the mistakes in students' speech noticibly facilitates and makes it more convenient to eliminate from the students' speech and to a certain extent prevent them.

In the study of bilingualism in bilingual individuals' speech we observed the tendency to using more simplified structures and models of the second language, avoiding those specific phenomena distinguishing it from the mother tongue and create certain difficulties in understanding and using the target language.

Especially in the process of the speech activity bilingual individuals try not to complicate themselves with comparatively unfamiliar and alien for their language consciousness, forms and constructions, and choose those grammatical forms and constructions which to some extent have similarities to their mother tongue or those which are adequate with the linguistic system of their mother tongue.

According to U.Wainriech (2011,42),"it is significant that in interference of the two grammatical models, usually the sample for imitation is the one which uses in its pardigm relatively independent and invariant models – we can say a clearer scheme". The idea that U.Wainriech claims is the fact, the reality. To what extent it is effective in conditions of bilingualism for the formation of bilingual individulas' proper speech skills?

From one point of view bilingual individuals' refusal from using alien grammatical and word forming morphemes of the foreign language significantly alleviates their perception of the second language, accelerates the process of learning and

communicating in the target language. From another point of view while learning the language at the academic level the above-mentioned reason impedes the effective perception of the language as more or less complicated grammatical categories of the foreign language are simply ignored and substituted by the simple ones, which are accessible enough for bilinguals. It is necessary to mention the fact that this process is observed particularly at morphological and syntactical levels in language contacts since the field of grammar is the sphere of language where bilinguals mostly find out juxtapositions and compare with the system of the mother tongue.

Deviations from the norms of correct usage are also observed in using exclusions from interlanguage rules of the target language. Bilingual individuals mostly strive for using those grammatical forms which are formed according to standard rules being challenged in the proper usage of exclusions. For instance, such mistakes of Azerbaijani students as incorrect usage of irregular plural nouns - –«foots» instead of «feet», «mouses» instead of «mice», «putted» instead of «put», etc . In the shown cases bilinguals automatically focus formal meanings of the words in use, "the meanings of paradigmatic relations to which morphological ways –affixation and other points", not taking into consideration special cases of the variation of root morphemes changing in the aspect of expression (Широков О.С., 1985, 222). The experiments for identifying the interference of perceptive character also show that in perception of the foreign language grammatical system, particularly, morphological structure of the English language, the comparison of the morphemes in Azerbaijani and English languages directly take place in bilinguals' (in our case Azerbaijani students') mind and under the influence of the system of the mother tongue the structure of the target language (the English language) is distorted. The essential task for those who teach the language is to alleviate the transition process from the system of the mother tongue to the system of the foreign language for learners taking into consideration discrepancies in grammatical structures of contacting languages before bilingual individuals perceive the language.

Both effective methodological exercises and data of the comparative grammar of Azerbaijani and English languages can be useful in this sphere.

As it was mentioned above, the mother tongue plays the key role in second language acquisition. The problem of the extent of the second language perception activeness by bilinguals and the degree of their perception of similar or strongly contrastive language phenomena characteristic to the target language need special linguistic investigation. Depending on this factor and individual characteristics of a foreign language perception by bilingual individuals of different age groups the level of mastering a foreign language by bilinguals and their language competence will be defined.

Findings

In the process of investigation of interference of perceptive character we can convince that the influence of the first language skills can be either negative, causing rude phonetic, grammatical, lexic-semantic and syntactical mistakes, or positive, promoting to overcoming challenges in mastering the second language due to similar structural features between the mother tongue and the target language. From this point of view in the process of perception and mastering a foreign language the phenomena of interference not only at morphemic, but also at other levels of the language must be taken into consideration and based on the results of the interference research it is necessary to compile effective language exercises for

appropriate audience. Certainly, the theory of language is directly reflected in its practical usage and many theoretical issues are solved precisely in the process of realization of speech activity.

The results of the theoretical and experimental research promote to profound and comprehensive development of not only Linguistics, but also other scientific disciplines related to Linguistics.

While learning a language, cognitive processes studied in Cognitivistics which focuses on the problems of Psychology, Linguistics, Philosophy, Neuroscience and the study of artificial intellect, play an essential role in a bilingual's mind. In the process of language perception, learning its rules and norms definite speech production strategies are realized (Резвина О.Г., 2006, 11). The principle of these strategies is that a foreign language perception except theoretical study of the language takes place by means of memorizing concrete speech utterances during speech production that is perception of the language in practice. Interference phenomena in such cases are minimized and can happen if a bilingual individual has problems with memory. Consequently, in the research of interference of perceptive character memory is one of the most important psychological factors in the second language acquisition. Bilinguals with comparatively effective ability to memorise perceived speech utterances succeed in language learning more often than those whose memory is trained weaker.

Except the above-mentioned factors in the study of interference of perceptive character bilinguals' physiological features related to the process of the foreign language perception which are unique and individual for every bilingual, have great significance.

Speaking about the perceptive character of interference we imply oral perception of English morphemes by Azerbaijani students as well as their oral and written reproduction in bilinguals' speech. The results of experimental research showed that the phenomenon of one and the same interference type, in our particular case- morphemic interference is manifested in unequal degree among Azerbaijani students with similar level of academic knowledge of English. This fact certifies that while learning a foreign language for prevention of interference phenomena bilinguals' individual language skills in the sphere of pronunciation, grammar, lexis, ability to communicate fluently as well as motivation, individual attitude to the target language and learners' emotional state should be taken into consideration. The learners' individual state is a crucial factor in the manifestation of interference in bilinguals' speech. Preconception in the wrong production of the foreign speech and fear of negative assessment by the teacher who masters the foreign language fluently as well as the peers who more or less effectively speak the target language is observed among the learners.

Such foreign linguists as D.J.Young (1991, 426-437) and M.Price (Price M.L. , Young D.J., 1991, 101-108) assert that psychological fear of making a mistake in speech in many cases causes the fact that such psychologically vulnerable students are practically inactive at the lessons of the foreign language. Similar research was done by the Turkish linguists N.Dalkilich (2001, 382-388), Kh.Ozturk and S.Chechen (2007, 218-236) and others who can see the link between students' performance and their fear of making speech mistakes.

In our experience while perceiving the English language by the Azerbaijani students besides the above-mentioned strenuous psychological factors causing the interference phenomenon, in some cases of even practical inactiveness during the lessons the influence of current assessment of their speech skills which they receive as a result of their

performance is also observed. This psychological pressure is directly reflected on some learners' language performance and academic progress.

The above-mentioned situations can be prevented with the help of quite experienced and trained in correlation with the appropriate methodology teachers who teach the foreign language focusing not only on the study of the concrete language material, but also on the ways of mastering a foreign language that would promote to further development and maintaining the learners' language level, since the language is a comprehensive phenomenon and its perfect mastering is the issue of time which is sometimes not limited to a definite academic program or standards.

## Conclusion

The current research of interference phenomena of perceptive character in conditions of artificial bilingualism revealed variety of factors affecting the second language acquisition which undoubtfully should be taken into consideration both by linguists in theoretical linguistic research and in Linguodidactics.

Bilingualism is a multifaceted sociolinguistic phenomenon which comprises linguistic, social, psychological and educative aspects. Bilingualism has both positive and negative effects on bilingual individuals. The positive effect is reflected in bilinguals' mental and emotional state promoting to their confidence and satisfaction by mastering the skills of the second language. The negative effect entails the challenges of learning the second language reflected in the phenomena of interference.

The current research differs from others in terms of bilingualism conditions. Apart from natural bilingualism, we investigated artificial bilingualism in English language auditorium conditions where the interference phenomena are more frequent rather than in conditions of natural bilingualism. We assume that students who study the English language professionally (for instance, students of Education faculty of Azerbaijan University of Languages whose future career is teaching English professionally) can be considered bilingual individuals.

As a result of the study of interference phenomena of perceptive character in the Azerbaijani students' English oral and written speech the role of the mother tongue is identified.

The following factors affect the interference phenomena in conditions of artificial bilingualism:

degree of genealogical kinship between the languages in contact;

unavoidable effect of bilinguals' mother tongue;

learners' deliberate usage of less complicated, simplified grammatical forms rather than complicated ones;

learners' individual skills of language perception, that is, memory;

learners' psychological features, that is, fear of making mistakes;

current assessment of their language skills.

The experiment done with the Azerbaijani students whose level of English varied from Pre-Intermediate to Advanced showed how successfully the students coped with the given tasks which aimed at revealing the phenomena of interference at the morphemic level of the language and the students' performance proved that those who were at lower

levels completely failed to accomplish the tasks and therefore need more listening practice voiced exclusively by native speakers of English; at the same time the students with poor performance and rude interference mistakes need verbal explanations of the potential interference phenomena and additional practice in doing exercises for preventing the deviations from the norm.

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# Conceptual Framework And Objectives. I, 'Madman': An Autosomatography of Schizoaffective Disorder and Mad Subjectivity

**Greg Procknow**

**Abstract** *This paper is a learning of schizoaffective disorder through the lenses of slasher-cinema studies literature, subjectivity camera theory, and Mad Studies. The author imports wholesale the language of slasher-cinema studies to help articulate his schizoaffective stories through an autosomatography. He recommends that the slasher subgenre of horror can be a progressive text to assist schizoaffective sufferers with understanding aspects of their schizo-symptomologies*

**Keywords:** Autosomatography, mental illness, Mad Studies, cinema studies, slasher films

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The 'mentally ill' masked 'maniac' is a marketing mainstay of the slasher subgenre of horror (Nowell, 2011). Madmen are evidenced prominently in the following motion pictures: *Schizoid* (1980); *Maniac* (1980); *Unhinged* (1982); *Madman*(1982); *Silent Madness* (1984); *Truth or Dare: A Critical Madness* (1986); *Delirium*(1987); *I Madman* (1989); and, *Psycho Cop* (1989) (Owen, 2012; Armstrong, 2003; Worland, 2006). Hollywood has produced well-over three hundred films in this strain of horror, spanning the 1970s to the present with maniacs coded as psychotic and donning a deep-seated insanity, whilst the murderer maintains a degree of normality. The disabled, psychiatric 'Other' is introduced as a means "to disgust the audience [and] reaffirm their normalcy" (Phillips, 2012, p. 69).

Slasher films best represent the realities of 'schizo'-subjects (Nowell, 2011). Screenwriters inscribe these subjects as 'schizophrenic' and suffering from a panoply of psychoses such as delusions, and auditory and optical hallucinations (Owen, 2012).

Slashers are all too human, and take us slightly "beyond the bounds of what psychiatric texts properly describe" (Knight & McKnight, 2003, p. 214). Imbuing the threat with mental illness adds depth and complexity to the slasher. Yet, while the 'mentally ill' monster takes on a purposeful and complex context, mental illness continues to threaten and disrupt normates' notions of "human identity and social normalcy" (Yeo, 2014, p. 79). Academics and researchers preclude space for inverting non-mad/mad dynamics, highlighting salient mad roles in cinema, or contesting the sick and passive roles characters not in their right mind assume (Procknow, 2019 in press).

Cinema depicts 'lunatics' and their mental distress in a rather sanitized manner (Harper, 2008). Critics of this subgenre ignore the differences between factual and fictive, and attempt to "censor fiction as if it were reality" (Cowie, 2003, p. 28). Out of fear of being branded psychopathic themselves, academics have been discouraged from drawing progressive readings from slasher subtexts (Nowell, 2011).

I preface my story by stating how I'm implicated in this paper as someone who has lived with schizoaffective disorder for the past twenty years. I narrate my storied self as a psychiatric consumer, male, early thirties, ex-criminal, who resides far below the poverty line. I tap into the mad lexicon and reclaim words such as: 'mad', 'crazy', 'insane', 'schizo', 'lunatic', and other time-worn terms oft-used to denigrate psychiatric subjects to refer to my neurodivergent self (and, unfortunately others) throughout. Whilst I struggle to unseat pejorative terminologies and am at the same time bound by them psychically and culturally, I find it, nevertheless, difficult to resist them in sane hegemonic cultures that vilify those of us with schizophrenia or schizoaffective diagnoses. Ignoring this tension, I problematize, and place these pejorative words in single quotation marks to signal them as reclaimed terms. People whose lived experience is deemed mental illness struggle to gain "equality for their experiential knowledge" (Russo & Beresford, 2015, p. 155). There is a dearth of research on 'brainsick' academics' own (dis)embodied experiences with psychic difference (Procknow, 2017). The silencing of our subjectivities has nourished a culture of complicity in our mental 'Othering' (Procknow, 2017). Rarely have pedagogues self-disclosed their mental health statuses when discussing mad matters (Procknow, 2017). Within academia there is a poverty of psychic disability disclosures, specifically amongst men (Brookfield, 2017).

Cineaste scholars have focused solely on victim-first analyses, as opposed to that of the perspective of the aggressor (Clayton, 2015). Little is known about the ways in which psychiatric patients are figured into slasher storylines (Phillips, 2012), specifically 'schizophrenics' (Owen, 2012; Stout, Villegas, & Jennings, 2004). The papers that do exist are qualitative (Chmielewski, 2013), descriptive, or single case studies, where only a few exemplars of one or two movies have been undertaken (Owen, 2012). Slasher films have the ability to "open a path toward critical reflection" (Freeland, 2003, p. 205). Critical self-reflection is needed where mentally ill viewers narrate how slasher films affect and influence them (Worland, 2006; Chmielewski, 2013). My autosomatographic vignette of learning insaneness is a dialogic, counter-hegemonic exploration of coming by schizoaffective disorder and making sense of my altered states through the subjectivities of the slasher and subjective camera lens theory.

This paper is structured as follows: Firstly, a conceptual overview of subjective camera lens theory is provided, namely for how it imbues perspective and a human mask to 'mentally ill' slashers. Secondly, autosomatography is introduced as this paper's methodology, and intertwined with Mad Studies theories that together look to restore strength to mad subjectivities. Thirdly, these theories are applied and related to my own autosomatographic account of schizoaffective disorder, specifically the auditory hallucination state that this disorder gives rise to that I call my 'alter.' I locate myself in the literatures of slasher film criticism/theory and reflect upon the subjectivities of the celluloid slasher that are germane to my own struggles with schizoaffective disorder. Only theories where slashers with psychiatric histories borne out through the lenses of subjective camera angles were engaged. I use this language to better articulate and elucidate my story. Moreover, I discern more about my alter through the scopic lens of the slasher's own schizo illness, such as learning that the language, personality, and face of my alter are distinct from those that my conscious self embodies. This paper concludes by suggesting that myself, like the filmic 'mad' murderer, is unable to return to sane normalcy.

My large-scale motivation for authoring this autosomatography is that I've noticed a shortage of reflexive accounts by mad-identified or psychiatric consumer authors and their experiences with intractable, serious, and persistent mental illness in Disability Studies and Mad Studies. Although, both disciplines call for the centering of "experts by experience" knowledge(s), I have found scant research in Mad Studies where consumerist subjectivities are actually being posited. Put simply, I'm troubled by what I perceive as pro-survivor (and to a lesser extent, ex-patient) praxis and anti-psychiatric knowledge(s) taking precedence in Mad Studies (Sweeney, 2016). This concerns me because survivor and anti-psychiatry scholarship seem to vilify consumers for sustaining Big Pharma.

No other cultural medium foregrounds madness like the slasher strain of horror. Therefore, I maintain that the slasher subgenre is a staple of Mad culture. That is why I find the paucity of schizophrenics' own stories of how screenscapes of madness have been used to unpack meaning about their psy-diagnoses disconcerting (Chmielewski, 2013).

Lastly, I believe it is important to put my perspective out there so that I can be authentic and authentically mad. To say one suffers from psychosis is one thing, but to narrate the shape that one's psychotic breaks take is all too absent from Mad Studies. This paper is an accounting of negotiating psychic space with a schizoaffective disordered 'alter,' specifically before I entered into the psy-regime as a patient (Foucault, 1994).

**Subjective Camera Angle Theory**

Subjectivity shots subsume viewers behind the murderer's mask in order to see what they see. In the slasher subgenre the matter of point-of-view, power, and vision is "explicitly foreground[ed]" (Sconce, 1993, p. 110). This subjective camera motif is a recycled narrative device relating the focalizer or the focalizing shot with the one who sees, yet is not revealed. To focalize is to present a scene through the first-person visuals of the stalker. *Halloween*'s (1978) four-minute prolog popularized the "subjective camera prowling through streets and houses that [located] the audience

into the optical point of view of the killer" (Worland, 2006, p. 101). As spectating subjects, our visuals are mediated by the slasher's steady, static, omnipresent gaze captured through the lens of a single-take, steadicam (a mechanical device used for smoother recording), or a hand-held tracking shot that sutures spectators into the film (Neale, 2004). The visual trope (a recurrent theme) of the subjective camera angle, its furtive, prying scope accompanied by the stalker's raspy exhales and footsteps marks their "sadistic-voyeuristic position" (Genter, 2006, p. 111). Point-of-view shots and the *mise-en-scene* collude to confuse spectators and mask the psychopath. The mise-en-scene is a pastiche of camera angles, lighting, locations, and characters that "distinguish the normal - and the audience - from the deviant" (Phillips, 2012, p. 68). The murderer's features are obscured until the film's denouement unmasks them (Worland, 2006). Narratives of discovery confirm or deny the verisimilitude of the protagonist's derangement: "the point of entry for an exploration of how to sort out the normal from the pathological through identity and representation" (Needham, 2002, n. p.). Our spectatorial gaze is as a co-conspirator, collapsed, and coerced into complicity, turning their murderous perspective "into an analogue of the audience's viewpoint" (Telotte, 2004, p. 25). This analogue thrusts us into the murderer's psychoticism (Robinson, 2012).

In slasher films subjectivity shots signify mental illness and mental illness is synonymous with the 'maniac' (Dika 1990; Robinson, 2012). The instability of point of view has been characterized as a "syntactic characteristic of the genre" (Roche, 2015, p. 22). The first-person point-of-view of unhinged, diegetic 'psychos' is a narrative in and of itself, "push[ing] forward [the killer's] experience of psychopathology in the form of a [mental illness]" (Anderson, 2003, p. 299). Slasher films reserve these shots for those of unsound mind in order to place viewers "repeatedly in [their] position, seeing what [they] see, tempted to feel what [they] feel" (Dickstein, 2004, p. 51). Subjectivity shots grant us glimpses into the madman's interiority (Dika, 1990). Therefore, I story how subjectivity shots have granted me glimpses into my own critical madness, and my autosomatography will provide readers with snapshots of these glimpses.

Slasher films waver between objective (where the audience are onlookers only) and subjective camera angles. Few films are seen entirely through either an objective or a subjective lens. With that said, viewers come to know that soundness of mind is reflected via objective angles, whereas unsoundness of mind is conveyed through a subjective, single-take steadicam. This is one way in which spectators are able to make the connection between unsound minds and first-person perspectives.

Many slasher films open with scenes inside an asylum (e.g., *Stepfather II*, 1989; *Silent Night Deadly Night II*, 1987; *Splatter University*, 1984; *Angst*, 1983). These scenes are often shot objectively. The sanitarium is a place of objective, positivist, and linearly formed understandings of the neurobiology of mental disease (Sweeney, 2009). The 'mad' incarcerant is medicated, seemingly stable, and epistemically violated. The positivist, objective camera shots are ordered as sane and psychiatrically-owned. However, only when, or after, the 'psycho' flees the asylum is their subjectivity restored. This subjectivity is indicated to the viewer by the use of subjective camera angles. Therefore, their escape and subjective recovery appears to be an affront to psychiatric objectivism – no longer are they medicated and stable patients. Slasher

scripts that infuse killers' subjectivities "suggest how easily and fully our normal world of appearances can be shattered by the intrusion of a harsh new reality" (Telotte, 2004, p. 26).

Herein, I contrast the slashers' own unstable, untreated, volatile subjectivities to narratively constitute my mad subjectivities, when I too was unhinged and free from the remit of psychiatry. I recognize certain cinematic elements to be representative of a knowledge or ontology of madness through subjective shots. For example: when the murderer's interior/exterior is ruptured and polyphonic voices, personalities, or identities emerge; the paranoia of seeing and being seen (stepping in and out from behind objects); and a perverse voyeurism that intrudes into the unsuspecting lives of sane victims.

Qualitative research that captures mad perspectives demands that researchers "embrace subjectivity, look for multiple answers, and assume that there are many ways of knowing" that are forlornly different from the mainstream template (Gewurtz, Moll, Poole, & Gruhl, 2015, p. 204). As a mad-identified, genre familiarist I have a more holistic knowledge of cinematic madness "because [I can] access…mainstream discourse [as] well as [my] own" (Faulkner, 2017, p. 506). As a mad spectator, I have full spectatorial focalization (a cognitive advantage over sane characters, and objectivity), and inside knowledge of the 'outsider' (Roche, 2015). On the contrary, normates have impoverished visuals (Roche, 2015). To their chagrin, so-called normals must wait for the protagonist and their coterie to be brought into the ocular fold of the focalizer, confirming the coincidence of insanity. As a schizo-spectator I am afforded "a place of observation, knowledge, and critique comparable to that of other identity positions" (Erb, 2006, p. 47). This schizoaffective accounting entails a critical self-reflexivity, where I scribe my subjectivities as the creator of my own mad analysis and theory to subvert mainstream media and psychiatric scripts (Beresford & Wallcraft, 1997). My schizoaffective disorder represents "a rich critical interpretative lens" permitting me access to absolute truths about life with an intractable mental illness (Castrodale, 2017, p. 51). These epistemic 'truths' are absolute, insomuch as they are self-evident to me.

**Methodology: Autosomatographical Scripting of Mad Knowledge**

This paper switches between the disciplines of cinematic criticism/theory, Mad Studies, and the methodological orientation of critical autosomatography. Slasher films are used herein as a (psycho-)analytic template for making sense subjectively of my 'alter,' rather than my madness serving as an interpretative lens for the analysis of slasher films.

Through the methodology of autosomatography I delve headlong into the scopic gaze of the slasher to ascertain the ways in which deranged states are structured and storied, and how their scripted fictions and my story intersect and bear out. Autosomatography is a first-person narration where I begin to unpack and make meaning of my suffering and illness (Couser, 2016). This methodology allows me to reclaim the right to speak about my psychiatric disease and politicize my psychoses free from further pathologization (Costa, Voronka, Landry, Reid, McFarlane, Reville, & Church, 2012; Couser, 2016). My autosomatography is a performative utterance that attests I can capably articulate and inscribe meaning to and about my mental maladies

through non-pathologizing objective and subjective lenses (Couser, 2016). This autosomatography evolved into a 'personal narrative.' This narrative entreats my schizoaffective disorder as its phenomena and focuses on life events that have sculpted my understanding of this disorder thus far (Ellis, Adams, & Bochner, 2011). In this critical piece, I survey 'Self' as 'Other,' and gift my schizoaffective suffering forward to neurotypicals so that they may get "a glimpse into a world the majority ignores" (Malhotra & Rowe, 2013, p. 10). I share my schizoaffective stories to colonize sound-minded psychic s/States with my psychoticism, to infect normals with this 'brainsickness' that the greater sane body politic has, in part, infected me with. This autosomatography is comprised of a series of gritty, subversive stories which challenge the hegemony of saneness by privileging the frenetic ramblings of a 'raving mad' academic. This autosomatographic text is also intended to undermine 'regimes of truth' (LeFrançois et al., 2013), and recuperate my narrative(s) from the discursive structure of media sensationalism and pathologization. Lastly, this personal narrative is a non-pharmacological stratagem for shoring up stocks of individual resilience to prevent psychotic relapse (Costa et al., 2012; Russo & Beresford, 2015). Guiding my autosomatography is the following singular question: how has slasher-cinema and subjective camera angle theory been instructive in teaching me about my madness and alter?

When I was twenty-two my mental health was inscribed by two psychiatrists as schizophrenia, and later rebaptized as schizoaffective disorder by a third when I was thirty. Schizoaffective disorder is a complicated condition to diagnose and treat (Ayd, 2000). The diagnostic criterion for this disorder is outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR). Schizoaffective disorder follows the same prescriptions used in diagnosing manic, mixed moods (in bipolar disorder), depressed, and schizophrenic states (Ayd, 2000). Schizoaffective sufferers experience uninterrupted manic and or major depressive episodes, or mixed episodes while embattled by hallucinations, delusions, or disorganized speech or thinking (Ayd, 2000).

This schizoaffective storying contextualizes my psychosis, the alter which it birthed, and my once-desired return to sane normalcy. Forthwith disclosing my psychic status and stepping out from my 'mental closet' (Noble, 2005) has been a tiring attempt at being authentically mad. Many of my disclosures to date have divulged the bipolar side of the schizoaffective spectrum (Procknow & Rocco, 2016). Shame and fear have made me conceal my schizo-symptomologies. Mentalism (the belief in my own psychic inferiority) (Chamberlin, 1990) hindered my help-seeking from the age of fourteen to twenty-two, and had me keeping my 'schizo' woes secreted for the next nine years from family and friends.

The pathogenesis of my psychiatric illness coincided with my sexual maturation. Around the time I reached puberty I withered into an existential depression, a darkness that still subsists today. My normal world had become 'Otherworldly'. My first psychotic break followed closely my first depressive episode, birthing an audible, hallucinatory, male alter. I refer to this hallucination as my 'alter' or my psychotic 'Other'. He is a command hallucination (auditory). Command hallucinations instruct bearers to grimace, attack others, self-harm, commit suicide or homicide (Ayd, 2000). During the first year he appealed to my squeaky vocularity and pimply-faced exterior.

His voice was more masculine: aural, external, and within hearing range. As the days turned into months we grew close. For reasons unknown, he later turned on me. He began to sever the vitals of my sanity by flaying and eating away at the raw meat of my neural matter. He harangued me to self-harm, gestured me to leap from buildings I ambled by, and screamed 'Jump!' when cars, trucks, or subways careened passed me. His psychotic posturing worsened when in the company of sound minds. Eventually, his psychoticism blistered through my psychic field and began dismantling the physical. He inscribed me a dejected, weak, and unhealthy exterior. I spent my entire youth snorting a sundry of substances that only masked my outward symptoms.

That self-medicated mask made me appear sane and normal to those who chalked my madness to substance abuse rather than to onset schizoaffective disorder. His sway over my subconscious shifted my mind off-kilter. I experienced anxiety over this loss of sanity and desperately scrambled for wholeness and stability. When substances failed to drive him away, or were found wanting, I turned to the slasher subgenre of horror, originally in an attempt to manufacture sane masks. Shortly thereafter, I started to infer more about my condition through slasher screenscapes.

This autosomatographic vignette of learning insaneness through slasher films focuses on snapshots of isolated moments that have emerged as narratable. Moreover, an epistemological pluralism comes into play here, where the knowledge(s) of my conscious 'self,' unconscious 'alter,' and the diegetic 'madman' converge.

The murderer's scopic gaze has informed my own knowledge construction about schizo-states. I do not assume the scopophilic drive as a device for cinematic pleasure, and to intrude upon the privacy of "others from his/her hidden position in darkness" (Giles, 2004, p. 39). I use this scopophilic lens to interrogate the sane body politic's synthetic sanity and the madman's illness. This drive is reserved for making meaning out of mental illness through the slashers' scopic field, psychoses, and their violent encounters with sound society.

**Resisting Sane Normativity**

Slasher cinema subtexts are a psychoanalytic, socio-cultural lens through which I make sense of the madness that my psychotic 'Other' perpetrated. In the proceeding sections, I will lead the reader on a journey of five progressive, non-linear states of being/knowing in relation to the slasher subgenre of horror. The autosomatography starts with a story of how my alter had influenced me to distrust sanity, and jaundiced my view of saneness. Next, I detail the fears I had of psychiatry that had led me to stave off disclosure and resist psychiatrization. More specifically, I was fearful that institutionalization would make me maniacally violent. Then, I ruminate over how slasher cinema can bring understandings of varied, ruptured polyphonic strands to bear on reflections of alterity, such as the voice that my alter assumed, and how he mapped madness exterritorialy on my mirrored reflection (rupturing outward). In the fifth and final section, I conclude that there is no return to sane normality, or sane normalcy, and how this conclusion has led me to accept the permanence of my mad state of mind. Overall, the paper would appear to suggest schizoaffective disorder as fractured and comprised of non-linear polyphonic branches (or expositions) of experiences. Each exposition serves as an informative standalone section. However,

when these non-aligned threads are knitted neatly together into a patchwork it will, I hope, give readers a fuller account of my life with schizoaffective disorder.

In the figuration of the diegetic monster "it has also become possible for…[us to] pay just as much attention to the figuration of 'normality'" (Urbano, 1998, n. p). The mise-en-scene screens 'normality' as a hodgepodge of boring, middle-class (Nowell, 2012), sane complacent, attractive, "young beneficiaries…[of] oppressive class structures that shaped social inequality in Eighties America" (Nowell, 2012, p. 96). Slasher films cast their target demographic into the diegesis "or, at least,…their mythical ideal" (Dika, 1990, p. 59). My madness was confluent and inseparable with poverty and a history of criminality. To see saneness normalized as being privileged and part of a middle-upper class upbringing stirred my alter into a frenzied disdain for sanity. He commanded that we terrorize 'sound' spaces, smash their strata of sane normativity, and disrupt normality in ways that press these spaces to be more inclusive of u/Us. (Note: 'We' or 'us' is used to mark a moment when he and I agreed). His angst remonstrated against these paragons of saneness and their neurotypicality. His psychoticism shone through with instructions to strike at, or attack, ostensibly normal, middle-upper class citizens, or to shield myself from their distrusting, fixed stares. We (the alter, slasher, and I) exist ontologically in disparate spheres from the ordinary, sane normative world. We witness their world spinning around us through schizoaffective spectacles. The mentally well embody par excellence that which we cannot be. We found common ground in this slasher subgenre, i.e. to dispatch the sane and normal, so that us abnormal could become the new norm.

In the subgenre "the way other characters [were] presented to us [was] thoroughly colored by [the killers'] own responses to them" (Knight & McKnight, 2003, p. 219). Audiences then "begin to feel the sort of disdain for its other characters that [the slasher] feels" (Knight & McKnight, 2003, p. 219). Slasher films desensitized me to saneness. As saneness seemed ungraspable, sound-minded s/States became the 'Othered.' Did this subgenre insulate me from the "horror of something painfully real?" (Solomon, 2003, p. 251). The painfully real, as he had convinced me, was sane normality. I came to denounce able-mindedness, and equated it as exclusionary and unrelentingly oppressive. He wallowed in the slasher's patently 'insane' angst against the sane body politic. Apart from the fictional, he implanted in my mind's eye delusory spectacles of their torn flesh mirroring the mise-en-scenic motto "where anyone [was] a potential victim" (Freeland, 2003, p. 209). Through their Othering, the mask I've fashioned has become suspicious and prejudicial of the sane.

In the slasher film, derangement of mind is misleading and implied rather than narratively shown. For instance, when first-person accounting is scripted as distorted (a narrative conceit), their narration of reality is not a true accounting of himself or his actions (Knight & McKnight, 2003). My alter's anti-sane stance disrupted my day-to-day dealings with familiars. His shouts and howls suffused and resounded throughout my mental space, drowning out neurotypical voices. He chimed in with a maligned, violent spin on their spoken version by introjecting a false narrative which altered their intent. He had me believing they were out to get me. My own accounting of these 'alt-realities' he rendered epistemically unreliable. He fed me discursive falsities to make me appear less reliable when I responded to questions normates never asked.

The diegetic mind can be scripted and nondescript, where contrarily mine was off-script and descriptive. As my illness relates to film, viewers with damaged minds are better able to discern which narrative elements are epistemically reliable, given our relatable knowledge(s) (Knight & McKnight, 2003).

**Resisting Psychiatrization**

Slasher films assume the 'psychiatric gaze,' i.e. a "camera's critical stance toward psychiatry and psychiatrists" (Donaldson, 2005, p. 32). Psychiatry threatens my mental difference and, in many ways, the existence of celluloid psychopaths. Although psychiatrists are positioned to treat the 'mentally ill,' they end up reinforcing "the very abnormality of those they want to help" (Stein, 1980, p. 636). I saw on screen how the fictional psychiatric firmament was as complicit in manufacturing madness as was biological or traumatic etiology. Psychiatry officiated mad s/States by unleashing them in order to name them (Foucault, 1994). The psychiatric gaze is blatantly obvious in *Trauma* (1993). Adriana Petrescu blames psychiatry for morphing her hysteria into psychosis. Petrescu was involuntarily placed in a madhouse that "[metaphorically] chops off heads and constructs docile, consuming bodies" (Badley, 2002, n. p.). It is where she fell victim to the domineering gaze, speculum, and scalpel of neuroscientists. She became a "product of the clinic in the Foucauldian sense" (Badley, 2002, n. p.). She thereafter avenges the loss of her sanity, and assails the psy-professionals complicit in her psychiatric assault by using a luggable, makeshift garrote device to chop their literal heads off.

I was afraid of being dumped at the doorstep of the asylum where psy-scientists would slash-and-burn all subconscious terrain where my abnormal alter had never invaded. I dreaded that the asylum would officiate and mediate the alter from his nether position in my mind to the forefront, surfacing it, unleashing it. I refused to be churned out of the madhouse even madder than I had been upon entering it. The screened 'madman' struggled to retain semblances of his pre-psychiatrized 'Self,' the person he was before first entering into it. I was terrified of being scurried off, straight-jacketed, and placed into padded accommodations. I feared that such a psychiatric assault would provoke him into permanent, psychopathic existence. I thought about how I would escape this 'regime' and its violence, and worried about what motives they would ascribe to my flight. Would they think that my alter had colonized what was left of my sanity?

Patients fleeing the psychiatric apparatus are equated in this subgenre as aesthetically violent and dangerous. So it was with Michael Myers from the *Halloween* franchise, who fled Smith Grove's sanitarium and set upon a killing spree. I believed that escaping the asylum would have branded me violent and non-compliant. I feared that being tarred a 'lunatic' would send me spiraling further into psychopathy, that my alter would bleed into the physical and I would become the cinematic pathological insane type. Therefore, I asked: could I be trusted within healthful hegemonic structures without attempting to threaten or disrupt them? Would I retaliate against those attempting to capture and restore me to the asylum? Slashers would much rather spill blood and respond with violence when threatened with re-institutionalization. They will resort to any gradation of bloodshed to evade further psychiatric assault. Take ex-patient Evelyn Chambers in the psycho-biddy

classic *Mountaintop Motel Massacre* (1986), who overhears her daughter's prayers when genuflecting to a makeshift shrine honoring her deceased father: "Daddy, got to talk to you its mommy she's getting sick again. I think she needs to go back to the hospital. She told me if I ever mention it again she was going to get me." The mere mention of re-hospitalization stokes Evelyn into a frenzy. Evelyn retrieves and swings a sickle aimlessly about the room, dismantling the shrine with one roundabout motion, and ending with the curvature blade piercing her daughter's neck.

I dreaded that the inner workings of my mind gone 'mad' would be deftly silenced. I believed psy-scientists would laden my truths with lunacy and doubt that my hallucinatory 'Other' was capable of non-violently co-occupying sane space. Epistemic warfare would be waged against my truths. Many slashers deploy this epistemic device. For example, Cynthia in *Bad Dreams* (1988) awakens from a thirteen-year-long trauma-induced coma. Psychiatrists deny the verity of her truths. Her psychiatrists knew her illness was non-existent, but yet concealed this fact from their charge and instead harbored a sinister, ulterior motive. I worried that psychiatrists would presuppose that I was non-sensible enough to deny my alter criminality and deter his threat to hegemonic saneness. In most slasher films "the killer [can] be in the victim's space [and] choose[s] not to attack" (Dika, 1990, p. 22). I learned that, I, like the diegetic slasher, can swap in and out of (ab)normalcy and contain my psychopathology when brushing shoulders with normates. This will continue to be the case as long as I continue to deny him physicality, and not allowing the fictional and representational to boil over off screen into reality.

My Alter's Voice as a Polyphonic Strand

Voice identification within this subgenre can be narrative subterfuge. The 'maniac's' voice can cause confusion and rupture the borders of subjective/objective and interior/exterior (Erb, 2006). Psychotics in *New Year's Evil* (1980) (use a voice box), the *New York Ripper* (1982) (deploys Donald Duck's quackery), and *A Blade in the Dark* (1983) (assumes a high-pitched female's voice) are given a secondary voice to use during their assaults. In each of these films the murderer's dominant voice and center of vocular identification is concealed, in turn masking their identity. In *Psycho* (1960), Norman's deceased mother vied for vocularity while Norman struggled to retain his own. Since Norman is himself and his mother, his vocularity vacillates between the two: the real and the deceitful. The 'deceitful' secondary voice "spread[s] psychotic effect from one character to another" (Erb, 2006, p. 56). A person with a history of alterity can evince polyphony when they have two or more voices (Walker, 2011). Polyphonic voices are naturally non-linear. However, in mental illness linearity is possible (Walker, 2011), that all selves can coexist and be linearly stable along the same spectrum of alterity harmoniously rather than discrete and autonomous selves, shorn of co-consciousness (Walker, 2011).

In *A Blade in the Dark* (1983) spectators can't see the face of Linda. Linda is Tony Rendina's feminized alter personae (both acted by Michele Soavi). We are unable to discern whether Tony's vocular rage "is an instance of external sound" (Tony speaks aloud as Linda and for himself), or as an internal sound (or do both voices only linearly exist in Tony's mind) (Erb, 2006, p. 56). The vacillation between the inside and outside gave me thought about my audible alter and whether his aural, monotonic voice was an

instance of internal vocalization. Or, perhaps, had the inside ruptured into the outside? Secondary vocularity granted me a glimpse into the maniac's interiority, and, subsequently, a glimpse into my own. My conscious narrative never cedes whole, unitary vocular control to him or his nonsense. His intelligibility I've relegated to accessory status. His vocularity resides in the inside, and as long as I stay stalwart in denying him externality, his threats remain interiorized.

My alter's voice is more than a frayed, polyphonic strand, but rather an authoritarian personality that cuckolds my sanity. Diegetic 'maniacs' "incorporate the personality of an authoritarian into their psyche" (Robinson, 2012, p. 39). They don't know that their "own mind…is actually creating the alter ego" (Robinson, 2012, p. 39). When realizing that my alter's auditory signatures were internal, I mapped his personality onto the onscreen monster. I surmised through these films that hallucinatory states inhabit and stalk the nether recesses of the subconscious. He was not some proximal, somatic manifestation trailing in my footsteps. Insanity is amorphous and a corpus without flesh. My body and mind, much the same as the diegetic madman, bear my flesh so that through the narrative of discovery my psychic viscera becomes readable. I believe my alter is a symbolic stand-in for a father figure to fill the vacuum of being born and raised fatherless. I embody aspects of his personality with short bursts of anger and frustration. Did my childhood of poverty in a single-parent home breed a latent anger within 'us' toward conventional mother-father coupling, where the regimes of sane normativity resembles that of heteronormativity?

**Mapping on the Madman the (Un)known**

The slasher subgenre arouses "in us a strong desire to know something unknowable" (Freeland, 2003, p. 204). In slasher films split, cracked, or shattered specular surfaces are narrative devices that designate a character's mental state as undergoing psychosis (Goodwin, 2014). When maniacs stare in a split, shattered mirror their mental Otherness and monster-like qualities are accented and return the gaze (Goodwin, 2014). The splintered mirror symbolism helped me understand how my alter frames and projects a fragmented me. When I glance at myself in the mirror, the mirrored, besotted 'Other' gazing back isn't real. I learned early through slasher consumption that my mirrored projection and my mind's projection were two disparate events (or entities). My psychoses halved my face as (un)masked. In the mirrored image 'known' and 'unknown' geographies were mapped. This narrative element is regarded as a 'doubling motif.' The "motif of the mirror image or double" often symbolizes the slasher's conflicted psychology (Knight & McKnight, 2003, p. 219). My left-side was the 'known': the 'known' that still wished for invisibility. This schism imprinted on the right half of my face the fragmented visage of the 'unknown.' This 'unknown' my deluded alter staked claim to. He mutinied with his voice, howling for wholeness. The 'unknowable' was a delusional construct he created to invert the well-trodden psychic/physical dyad. The unknowable side I read as part-fiend/friend, dead pan and expressionless. My right eye drooped, appeared heavy and lazy. Only I could gaze upon him. Both the 'known' and 'unknown' were constantly infighting and had to mediate facial congruity when in sane company. For instance, an entire year passed when I could only comfortably smile, laugh, and speak through a slightly ajar left side of my mouth. My alter framed the 'unknown' mirrored facade as a projection, "revealed

to be false, or at least not always accurate" (Donaldson, 2005, p. 42). The camera here restored to me "what the [diegetic] schizophrenic subject [had] threaten[ed] to destroy: reliable perception" (Donaldson, 2005, p. 43).

Audiences tend to be less interested in the slasher's "abnormal psychologies." Rather, they revel in the slasher's sheer outer ugliness that makes readily apparent any "internal workings of [their] anguished self" (Schneider, 2003, p. 175). The 'reel' of my psychic 'horror show' did not need to unspool in the stares of able-minded audiences. My alter, I knew, did not need flesh, only fleshing out. I learned through these films that my accessible outward appearance does not have to be associated with the grotesquery that lays within.

**There is no return to Sane Normalcy or Sane Normality**

Sane normalcy and normality are nuanced, and refer to two dissimilar relapse events. Once one is psychiatrized for them, to fall back to a non-mad state is a myth (Erb, 2006). Or, I surmise an earlier state to mean 'sane normalcy.' Madness is a fixed ontological condition. Our disturbed minds can never be completely eradicated. On the obverse, sane protagonists seek the restoration of time and space back to their heydays of 'sane normality' (Goodwin, 2014). When characters of sound mind organize and militate against madmen, they strive to restore time to an idealized past. I surmise such heydays as 'sane normality' (Robinson, 2012).

When my deviance is reified in popular cultural artifacts as an aberration of the norm, I'm reminded of how insurmountable restoring sane normalcy is. This constitutes an assault on my dissimilar state(s) of 'Being.' Having begrimed my mad authenticity for so many years to fit into the healthy-minded millwork to no avail, I, instead, accepted my schizoaffective disorder and altered states as authentic states of knowing and 'Being' in the world. I had shed my aspirations of sane normalcy. I began to intimately engage in piecemeal mad disclosures to normalize my psychoses. I repositioned my mental maelstrom as a human variation worthy of embrace. The more I attempted to shake my psychic tree of its traumatic or biological etiology, the less of an advocacy identity I took on to help myself and 'Others' with schizo-diagnoses.

In order to normalize schizoaffective disorder, I came to trust two realities: that the schizoaffective condition is relatively constant and permanent; and, I need to repose confidence and trust into my symptomologies - their validity, appearance (aural, yet externally non-existent), and regularity (substance abuse, sleep deprivation). I had to cede that these symptoms were innocuous. For example, when my alter ekes back into short interludes of existence I know to ready myself for instructions to self-harm, and for a verbal onslaught of sane 'Othering.' Medications only mask my interiority and will never dispose the undesirable within it. Learning to live with psychiatric disease as an infinite condition, and calibrating the correct dosage of medication has augured well for me. I accept that these injunctions won't necessarily bode well for all schizoaffective sufferers. I do envisage myself as a pro-consumer who has accepted a sick role, passivity, and a certain degree of docility as a service user.

On a final note, I gained subjectivity of my condition through abjection (Jerslev, 1994). My alter's angst (e.g. anti-saneness) had taken on the contours of the irrepressible horror riven within 'Self' (Jerslev, 1994). By psychically distancing myself from his brimming angst I took up the process of 'abjection' (Kristeva, 1982). I had

separated myself from his rage, and apportioned him to the outside, given him bodily boundaries (by locating his angst and anger in the slasher's own), and ascribed his violence as the abjured and 'abject' (Cowie, 2003). My alter's hatred was what I could not contain - the abject. The abject as a non-object confirmed myself as the Othered subject (Kristeva, 1982; Jerslev, 1994), where myself as 'Other' was constituted in terms of a sane(r) 'ego'. His hatred, the 'id', came to represent the monstrous within me, that I repressed (but could never destroy), and projected the abjected "outward in order to be hated and disowned" (Wood, 2004, p. 111). Undergoing abjection, I took my alter's rage (object-now reviled abject) and decried it as detestable as a "way of creating difference" (Jerslev, 1994, p. 20). When I wedged myself from t/his 'difference' it marked the beginning of my subjectivity, where 'I' was being born, and subjectivity was constituted (Jerslev, 1994). Through abjection and acknowledging my alter's angst as the detested, I sourced the subjectivity needed to unpack meaning and make sense of his disembodied rage. Through subjective recovery I was better able to make sense of his interior position. Aided by medication and mindfulness he remains, most days, repressed in abeyance. We cannot exist linearly, for his irrepressible psycho-social instability can only be silenced by suppressing his entire being.

**Final Thoughts**

The corpus of slasher films are arguably educative and performative texts that have granted me a smattering of glances into the fictional alterity of diegetic psychopaths and the plastic sanities of the presumptuous, prototypical survivors. 'Maniacs' lacking *mens rea* helped to create fictive visuals through which my alter vicariously enacted his own anti-sane prejudices and violence.

Cineaste critics that lambast auteurs use of subjective camera angles to shoehorn spectators into adopting a killer's gaze are complicit in reifying epistemic injustices against 'reel' and 'real' mad citizens (Worland, 2006). Our poignantly felt experiences of loss of sanity are suffocated. Our motives behind inflicting insane rage are ignored and inscribed little, if any, justifiable significance (Harper, 2005). If normates could suffer the killer's trauma from their perspective this, I posit, would shatter the 'regimes of truth' that vitiate the epistemic value of our subjectivities. If the scopic lens were contrived to return voice to the disabled, queer bodied, or people of color, cineastes would, without peradventure, praise this as hinting progressive subtexts (Harper, 2005; 2008).

Admittedly, my autosomatography took on a noir-like first person narration - a less sanitized version than academic audiences are accustomed to. I comment herein only on the sickness I share with the all-too-human diegetic killer. I intimate inside knowledge of the 'outsider's' subject matter. As a subject matter spectator, I have epistemological and social resonance with the focalizer's repressed aspects as someone struggling with similar schizo-symptomologies. The slasher's scripts have also become my own.

Conceivably, the slasher subgenre may psychically damage some sufferers of schizoaffective disorder, who similarly may attempt to make meaning about their psychosocial disability from this subgenre's subtexts. Damage can be incurred in two ways: firstly, rather than focusing on the multidimensionality (and trials) of living with this alterity, mentally ill spectators might internalize themselves as despicable,

unidimensional 'Others.' This unidimensionality is stereotypical of 'schizo' slashers (Harper, 2005). This may result in developing, as I once had, an unsettling paranoia and anxiety about harming others. I assuaged these anxieties by asking myself what motivates the 'madman' to kill in the first place? This required a radical rethinking of diegetic victim dynamics. I began to contemplate the madman's motives. To do this I invoked and inverted Wood's (1979) theory that the 'monster threatens normality,' to instead suggesting that 'normality threatens the monster.' I began considering that the filmic maniac was, in part, the reel/real victim, fighting against sanism (the mental Othering of psychiatrized people) (Perlin, 2008) and psychiatric oppression. Perhaps the violence they enact is a subversive protest against sociopolitical suppression (Harper, 2005), sane supremacy, and "trying to right the wrongs that were done to [them]" (Robinson, 2012, p. 117). Rendering the madman into a figure worthy of humanization I consider to be my earliest entryway into Mad activism. By putting a human face on the celluloid mad subject it makes a case for slotting slasher films into Mad culture.

Secondly, I believe that some viewers, whilst using slasher films as a template to make sense of their own lunacy may encounter 'sane dysphoria,' where, the mentally unwell consume and idolize screenscapes of saneness, strive for sanity, and when realizing they cannot be sane suffer generalized malaise. Slasher films can desensitize psychiatrized viewers to 'scapes' of saneness and the sane supremacy the sane perpetuate in the same way that non-White viewers turn to Hollywood motion pictures to glean more about whiteness and white privilege (Shome, 1996).

I consume slasher films as a means of suppressing my alter's rage, not the alter itself. Firstly, I learned that psychiatry is only one way of containing hallucinations, and can never necessarily phase them out. Secondly, every film is a dual or double-viewing. My lucid, conscious 'Self' sees this subgenre for its saneness and envies it. Even though my psychotic 'Other' eschews screenscapes of saneness, these envies and detestations seldom clash or confront one another. He is complacent in his insanity. My ego conscious side of 'Self' learned insaneness to understand more about my alter, and how sane society organizes to subdue psychotic breaks from the mean. Since madness glossed over my veneer of human normality, I sought a reprisal, or a resurgence of innocence when I was comforted by and shrouded in sanity. In other words, a return to sane normalcy. This return is unlikely, and I know this. Instead, I began to challenge my mental models about saneness, and concluded that sanity was not right for me. I reprogrammed my ingrained models to accept 'insaneness' as my correct psychic s/State, ceded to treatment, and accepted the realities of my schizoaffective states. Sanity is far from sacred. I've come to understand that sanity is as much an absurd farce as insanity.

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# Authentic Voices, Authentic Encounters: Cripping the University Through American Sign Language Octavian Robinson

**Jonathan Henner**

**Abstract**

*Discussions on disability justice within the university have centered disabled students but leaves us with questions about disability justice for the disabled scholar and disabled communities affiliated with universities through the lens of signed language instruction and deaf people. Universities use American Sign Language (ASL) programs to exploit the labors of deaf people without providing a return to disabled communities or disabled academics. ASL courses offers valuable avenues for cripping the university. Through the framework of cripping, we argue universities that offer ASL classes and profit from them have an obligation to ensure that disabled students and disabled academics are able to navigate and succeed in their systems. Disabled students, communities, and academics should capitalize upon the popularity of ASL to expand accessibility and the place of disability in higher education.*

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It is common for deaf people to grumble about nondeaf people teaching American Sign Language and deaf culture in higher education institutions. As deaf people experience the sting of audism, ableism, and inequity, they pull back and situate this discourse within the larger notions of disability justice and social justice. Even though American Sign Language (ASL) has gone vogue, deaf people continue to remain with other disabled people on the margins of U.S. society. Inclusion and access to academia must be made not only for deaf and disabled students, but also deaf and disabled scholars and faculty, despite the cost.

Although deaf people in the western world have historically considered themselves as sociolinguistic minority groups separate from other disabled

communities, we recognize the underlying structural forces and historical, social, and cultural processes that shape deaf people's relations to society and the academy are tied to dis/ability and ableism. As appropriate, we refer to deaf people as a distinct population within the disabled community when speaking to experiences that mainly affect deaf people. However, we use the term disabled when referring to experiences that affect broader disabled communities, including deaf communities. We also suggest solutions via the concept of *cripping* the academy. Cripping requires that higher education institutions consider authentic voices, faculty, and encounters when offering disability-related content.

Explicit representation of disability among students, faculty, and academic discourse benefits everyone. In this article, we argue that American Sign Language (ASL) and Deaf Studies serves as an avenue for abled students, colleges, and universities to engage with disability in critical ways. ASL courses, unlike other foreign languages, give abled students the opportunity to transcend not only cultural boundaries but also the boundaries between abled and disabled in challenging what we take for granted in our understandings of normalcy (Annamma, et al, 2013). ASL also offers opportunities for educational interventions that work toward the ends of a liberal education.

And yet, several questions must be considered when analyzing the place of ASL education in higher education. Who should be able to teach ASL and disability related courses? How has the surge of interest in ASL affected signed language teachers, deaf and disabled academics, and deaf and disabled communities? This is not the first article to examine the appropriateness of nondeaf people teaching ASL. What this article does is examine institutional practices for offering ASL classes and considers how ASL can bring the benefits of disability to the higher education classroom. In our analysis, we extend Claire McKinney's (2016) concept of *cripping the classroom* to *cripping the college and university*, and more specifically, *cripping the ASL classroom*. To crip higher education is to intentionally create welcoming spaces for disabled students and faculty. It involves embracing disability scholarship and the study of disability across the curriculum. Cripping higher education allows students, administrators, and scholars to critically engage with questions of language, social control, and power surrounding disability. While McKinney's framework was about how professors can make their classrooms more accessible for disability and disability-identified peoples, our framework considers how universities can use ASL and Deaf Studies classrooms to increase the presence of deaf and disabled people on campus. It supports deaf people's needs as both students and faculty and enables an environment that is mindful of the varied needs and desires of deaf communities. Most importantly, our framework fosters intellectual engagement with disability. In this article, we examine how universities have profited from ASL while denying opportunities to deaf students and academics. We also explore ways that universities use ASL classes to further marginalize deaf academics. While *cripping* the university and having deaf leadership is fundamentally good for how universities engage with deaf scholars, if universities use the premise of cripping to force deaf scholars into limited roles within a narrow interpretation of the cripping paradigm, then cripping becomes weaponized against

deaf scholars. That is, if deaf academics can only teach ASL and do nothing else, is this good for deaf and disabled people and affiliated communities?

The contradiction between ASL as a cash cow (Brueggeman 2009) and how the community that owns the language is treated is particularly sharp in higher education. ASL classes are popular, while deaf communities find their cultural spaces overrun by nondeaf students from local ASL programs. Meanwhile, deaf people continue to confront access barriers in curricular and extracurricular activities on campuses and faculty employment. For example, in March of 2017, *The Daily Californian* detailed Nancy Barker's attempts to obtain suitable accommodations via signed language interpreting at University of California, Berkeley (Berkeley) (Shrivasta 2017). *The Daily Californian*, a local student run newspaper, described how Barker, a visiting deaf researcher, was frequently refused interpreting services by the Disabled Students' Program (DSP). DSP, which bills itself as a program that "…promotes an inclusive environment for students with disabilities," argued that because Barker was not actually a student, only a visiting one, they were not obligated to provide her with accommodations. The obligation to provide access fell on the department that invited her. In that same month, Berkeley began the process of taking down thousands of online instructional videos and podcasts in response to a lawsuit by the National Association of the Deaf (NAD), which claimed their content to be inaccessible to deaf people (Larimer 2017). Berkeley, which in 2016 had an endowment fund totaling 8.8 billion USD (Serpa 2016), explained that making what they called "legacy" media accessible not only for deaf people, but for blind people as well, was prohibitively expensive.

Berkeley is not alone in its exclusion of disabled people. In recent years, more than two dozen higher education institutions, including Harvard, MIT, and Berkeley, have been sued over campus accessibility issues. If higher education institutions are preparing their students to become engaged citizens, then what are their obligations to serve and engage the communities from which their students come? While the role of higher education institutions in maintaining diverse environments of race, class, gender, sexuality, and religion is clear, the inclusion of disability is less so. Higher education institutions benefit from the presence of disabled people and their contributions, including signed languages. Institutions that profit from ASL instruction must consider not only their role in the marginalization of ASL as a viable language for deaf children and marginalization of disabled people, but also whether they have an obligation to parlay some of their profits into work toward disability justice. Here we argue that disability justice is necessary for institutions that profit from the deaf and disabled communities. Higher education institutions are profiting from ASL instruction without providing a return on those profits for deaf and disabled students and faculty by removing barriers to admission, matriculation, and academic careers, while engaging in exploitative relationships with local deaf and disabled communities.

Disabled students and disability activists are familiar with the ostensible role of university disability services. These services are often perceived to exist not to provide true access and inclusion for disabled people, but to satisfy the bare minimum of legal obligations for access while remaining cost-efficient. Because of this emphasis on legal obligations and cost efficiency, disability services can become another barrier for

disabled students to navigate. First, disabled individuals must recognize they have a disability and that this disability requires accommodations. The disabled person confronts challenges in identifying with a disability because they must not only *come out*, which in itself is fraught with danger (Samuels 2003), but also claim a status which carries its own stigma (Marshak, Ferrell, and Dugan 2005). Second, they must prove to the university that their disability is deserving of accommodation. As both Sami Schalk (2017) and Alison Kafer (2013) remind us, not all disabilities have been recognized or are identifiable by the medical authorities. Finally, the disabled person must demonstrate that their preferred accommodation is feasible for the university, in that the accommodation is not too extravagant or expensive (Woodcock, Rohan, and Campbell 2007). One may have ASL interpretation, or a Communication Access Realtime Translation (CART), but likely not both. Accommodation requests must also be made weeks in advance, with no guarantee that suitable accommodations will be provided. While able-bodied students and faculty can wait until the last minute to decide if they want to attend an academic event, the same is not true for their disabled counterparts. For example, signed language interpreters are not automatically scheduled for all academic events (Davis 2013).

The difficulties deaf and disabled college students and faculty confront in receiving appropriate accommodations are contrasted by the success and popularity of ASL classes. Studies by Russell Rosen (2008), and David Quinto-Pozos (2011), among others have demonstrated that ASL course offerings have surged in both secondary and post-secondary environments. ASL course offerings increased by 437% in a six-year span between 2003 and 2009, and ASL is now the third most-taught language in the United States (Brueggemann 2009). Those who teach ASL are familiar with the appetite for learning ASL, as they manage waiting lists and address multiple contacts from students pleading for entry into closed courses. Colleges and universities have observed the popularity of ASL and seek to profit from offering ASL courses.

Deaf people are multiply marginalized within and outside of higher education institutions while signed language education offers tremendous profit for those institutions. Higher education institutions receive millions of dollars in grants for signed language research and attract prospective students by satisfying demand for signed language curricular programming; however, signed language scholars remain largely nondeaf, and deaf students struggle to get access to classroom discourse and information. Some institutions also capitalize on offering deaf/special education programs, disability scholarship, and training in the health care professions. Yet those same institutions balk at disability inclusion efforts, directing concerns to the costs of access. The intellectual, social, and cultural benefits from having deaf and disabled people in the academy and including disability scholarship in higher education curricula outweigh those costs. Deaf and disabled people provide a unique epistemology that enrichens the discourse and offers a different lens for thinking and learning (Robinson and Henner 2017). Furthermore, accessibility for deaf and disabled people improves institutional profitability. A number of recent studies show that inclusion and access lead to increased profit, innovation, productivity, loyalty, cost efficiency, and market shares (Lindsay et al, 2018). Such exposure better prepares able-bodied students for post graduate lives and the workforce, as well as for their own

likely inevitable brushes with disability (Robinson and Dechant, 1997; Leonard et al. 2002). In contrast to the influx of cash that ASL courses bring to higher education institutions, access and accommodations for deaf students and faculty are framed as a financial burden. This framing to justify denial of access and accommodation or exclude deaf people from being hired for faculty positions remain acceptable within higher education institutions. However, human, disability, and civil rights cannot be reduced to economic logic.

The benefits of having ASL instruction in colleges and universities are unquestionable and the campus presence of ASL is vital for cripping higher education (Bauman and Murray 2014). ASL in colleges and universities affords nondeaf students the opportunity to interact with disability and engage in discourse about the intersections between bodies and the society they inhabit. ASL classrooms present a forum for institutions to confront disability, systems and dynamics of power associated with ability, and linguistic inequity between spoken and signed languages. ASL reminds us that language is not limited to oral speech systems and that people can communicate complex academic ideas, craft poetry and stories, and share thoughts and feelings *without speaking through the mouth*. The presence of ASL lends credence to communication modes that empower disabled people, such as communication boards (Lupton and Seymour 2000). And, yet, the use of ASL is overtly political, given historical attempts to suppress and eliminate it (Baynton 1996). Thus, using ASL is defying normalcy on multiple levels as Americans grapple with prejudices toward languages other than English and insist that signed languages are not on par with spoken languages.

School systems, colleges, and universities still hire nondeaf people to teach ASL even though it is a resistance language of a marginalized community. But, ASL, when taught by culturally and linguistically competent faculty, offers us the opportunity to change the attitudes and popular beliefs that many nondeaf and able-bodied people have about signed language, deaf culture, and bilingual education. Attitudes toward signed language and respect for deaf culture play an important role in the advancement of linguistic human rights. These attitudes work in tandem with advocacy for bilingual education, the status of signed languages for access and citizenship, and the development of further research and documentation of signed languages (Murray 2015). As a party to the systematic marginalization of deaf people, offering ASL, deaf cultural studies, and Disability Studies courses offers higher education institutions an avenue to right the wrong that anti-signed language work has wreaked. And yet, simply having deaf faculty teach ASL courses alone is not enough. Higher education institutions need to critically examine how their health professions, interpreter education, and teacher preparation programs contribute to the undermining of deaf people's civil and human rights.

Through sound hiring practices, a balanced curriculum consisting of both language courses and deaf/disability studies courses, and nuanced co-curricular offerings, ASL education offers higher education institutions a valuable set of educational interventions that research shows "play a critical role in helping students increase their knowledge of other cultures, their cross-cultural sensitivity, and their capacities for intercultural communication and decrease their prejudice against

others" (King, Perez, and Shim 2013). Those educational interventions are critical in achieving the aims of social justice, disability justice, and a diverse participatory democracy. Higher education institutions should capitalize on the popular appeal of ASL education to promote interest in Disability Studies and Deaf Studies. ASL classes are also a viable springboard for students to engage with the notions of ableism, audism, and disability (Bauman 2004). However, higher education institutions that purport to value diversity, equity, and inclusion should critically scrutinize their hiring practices, curriculum, co-curricular offerings associated with their ASL programs, and the place of deaf and disabled scholars within their institutions. This is a question of social and disability justice.

As educational institutions rush to meet the growing demand for ASL classes, questions of equity, social justice, disability justice, economic justice, linguistic human rights, and cultural appropriation emerge. Fundamentally, who is qualified to teach ASL? What is the role of the deaf academic in the college and university environment? Is there a place for deaf scholars outside of the ASL classroom? What of deaf epistemologies and ontologies in the curriculum and research? Tension has emerged between deaf people and educational institutions as bloggers openly question how educational institutions determine the merits, fluency, and cultural competency of their ASL-teaching faculty (Suggs 2013; Lapiak n.d.). Some also wonder about the impact that inarticulate or culturally incompetent ASL teachers have had on an already marginalized community. Those of us who reside in deaf spaces are familiar with the boisterous nondeaf person who backs every incorrect assertion with claims that their [often nondeaf] ASL teacher taught them such. Administrators and committees in charge of hiring faculty at higher education institutions must pause and ask if their ASL teachers are teaching ASL through culturally affirming practices, or if the goal was about maximizing profit by increasing enrollment at the expense of access and inclusion (Brueggemann 2009). Along the lines of Disability Studies scholar Simi Linton's (1998) assertion, administrators, along with "…scholars of all stripes must recognize their moral and intellectual obligation to evaluate the gaps and faults in the knowledge base they disseminate to students which are a result of the missing voices of disabled people" (Linton 1998, 142). From a disability justice standpoint, administrators should ensure that those who teach ASL and deaf related classes are deaf. Authentic lived experience offers future teachers of deaf children, signed language interpreters, and others who interact with deaf people the best opportunity to develop critical linguistic and cultural competency that is essential to language acquisition and providing deaf children access to the world.

We propose schools prioritize the hiring of deaf people to teach ASL and to consider larger questions of equity, social justice, and disability justice in their ASL curricula. As Nirmala Erevelles suggests, "belonging and identity are not idle insertions into political discourse; rather they have critical implications for how the field of disability studies continue to expand and thrive (2014)." We argue that hiring deaf people falls within the praxis of *cripping the college or university*. It recognizes that disabled and deaf faculty members have valuable situated knowledge of lived experience with disability that enriches the learning experience. It is at *this* intersection where academia and activism meet in our work toward disability

justice. After all, how can schools "develop disability studies courses and programming without simultaneously pushing for increased access for disabled students" [and faculty]? (Jarman and Kafer 2014)

**The Case For "Affirmative Action": Preferential Hiring of Deaf Faculty**

Intersectional realities as well as historical and social differences among disability, gender, and race limit the reach of our analogies. However, research from marginalized communities suggest possible starting points of inquiry. For example, Nellie Mckay (1998) points out three central challenges to giving black faculty ownership of their community's literature production: a) the lack of a pipeline that consistently produces capable black scholars, b) an inability to dissuade white students, particularly unqualified white students, from becoming scholars in black related fields, and c) a meager pool of existing black scholars from which colleges and universities can hire. We posit that colleges and universities face similar challenges in applying disability justice principles to their ASL programs. As Michele Jarman and Alison Kafer (2014) suggested for Disability Studies, higher education institutions need "radical, innovative approaches to conceptualizing and increasing "access" in the academy" and to rethink "normative assumptions [...] and undo ableist assumptions about individual academic achievement (Jarman and Kafer 2014)" Like them, we demand that the growth of ASL and Deaf Studies be accompanied by a growth in access and opportunities for our communities. Our suggestions, in this vein, are described below.

First, there is an inadequate pipeline for producing deaf scholars who are knowledgeable in ASL and deaf-related disciplines. We propose that this is in part because of a long history of institutional violence against signed language, deaf people, and deaf culture. Signed language has been under concerted attack since the early nineteenth century by doctors, nondeaf parents of deaf children, and advocates for listening and spoken language educational paradigms. Those attacks were, and are, often steeped in eugenics, xenophobia, ethnocentrism, and racism. Signed language use has been legislated against, banned, and withheld from deaf children by nondeaf people. Active campaigns against signed language remain as lively today as in 1917 (Baynton 1996, Mauldin 2016). Attitudes against signed language have also left behind a legacy of trauma imposed upon deaf communities. Deaf survivors reveal their stories of childhood neglect and physical, verbal, and psychological abuse in the documentary *Audism Unveiled* (Bahan, Bauman, and Montengro 2006). It was common practice among educators of deaf children to whip children on their hands with rulers or yardsticks if the children were caught signing or gesturing. One of the authors of this article observed nondeaf educators, at a listening and spoken language school for the deaf, forcing deaf children to sit on their hands, and physically preventing the children from gesturing. Deaf people live lives closely intertwined with the consequences of those attitudes toward signed language. The 21st century adult deaf community in the United States grapples with rampant print illiteracy, under- and unemployment rates ranging from 25-75% among deaf adults, and the consequences of trauma, abuse, and neglect, among a smorgasbord of still other inequities (National Deaf Center for Postsecondary Outcomes 2017). Deaf people's barriers to literacy, education, and

employment are also complicated by a wide range of social factors including but not limited to socioeconomic status, race, ethnicity, gender, and sexuality.

Second, although nondeaf parents are discouraged from using signed language with their deaf children, teaching signed language itself remains a profitable option for nondeaf people. ASL remains a lucrative option for educational specialists who combine signs from ASL with music. Rachel Coleman (2017), a nondeaf mother of a deaf child, created *Two Little Hands*, a company which sells signed language educational material that stars Rachel Coleman herself, who only learned signed language after having a deaf daughter. Patty Shukla is another such example. Shukla combines what she calls "baby signs" with music to sell educational experiences to parents (Shukla n.d.). Another example of nondeaf people's success in peddling signed language without regard to exploitation is *Super Smutty Sign Language* by Kristin Henson (2013). *Super Smutty* is branded as a signed language book and was, for a time, categorized as a Deaf Studies book. The signs in the book do not resemble actual signed language used by deaf people and is not accurate. Henson's authority on the language comes from briefly studying ASL as an undergraduate. However, people purchase this book on the premise that the signs in the book are the real deal. No material produced by deaf or hard of hearing educators has had similar success. The material popularity of ASL is keenly felt among deaf signing communities as they watch nondeaf people make enormous profits from ASL while deaf people struggle with economic marginalization; ASL has become a form of entertainment, divorced from accessibility. But who owns ASL? As Maurer (2003) points out, languages can be considered owned by a community if it is part of "a cultural inheritance". The question of language ownership has attracted legal scholars (see Hutton, 2010 for examples). Hutton (2010) describes protests against corporations appropriating Maori and Mapuche languages. Thus, the conflict about who owns ASL is not novel. The injustice is not solely that nondeaf profit from ASL; but that signed language is being withheld from deaf children while nondeaf children and their parents are encouraged to learn it.

And even while deaf children are actively denied access to the language of their community, higher education institutions profit from offering ASL classes. Brueggemann suggests that for those whose budgets depend on enrollment and semester credit hours, ASL courses have emerged as a gold mine because they fill quickly and possess long wait lists (Brueggemann 2009, 29). Nondeaf people, many deemed as dysfluent and culturally incompetent by fluent ASL speakers, fill many ASL teaching jobs, enjoying gainful employment, while deaf signers grapple with employment discrimination and institutional resistance to the provision of accommodations. Deaf signers often find themselves passed over for teaching positions in favor of less fluent nondeaf signers with dubious credentials. Due to systemic inequities, particularly in access to higher education, nondeaf signers are more likely to possess advanced terminal degrees compared to their deaf counterparts. College and universities often find it easier and more cost effective to communicate with nondeaf faculty rather than absorb the cost of accommodations, thereby making it more difficult for deaf academics to get hired. As Kathryn Woodcock, Meg Rohan, and Linda Campbell (2007) point out, colleges and universities are disincentivized to hire deaf faculty (Woodcock, Rohan, and Campbell 2007). Such higher education products

contribute to the marginalization of deaf people and the degradation of ASL, while defrauding those with a sincere interest in learning ASL and about deaf people. Poorly taught signed language classes lead to unqualified, dysfluent signed language interpreters who think they are qualified, which has negative implications for deaf people. The practice of hiring nondeaf people from undergraduate academic programs in interpreting, Deaf Studies, or ASL presents a significant challenge because many of those graduates lack sufficient fluency and cultural competency to teach ASL language courses, let alone more interdisciplinary courses like Deaf and Disability Studies.

Some colleges and universities attempt to provide legitimate ASL and deaf culture experiences by hiring nondeaf signers who are children of deaf parents and therefore are considered heritage signers (see Hoffmeister 2008 for a discussion of nondeaf children of deaf parents). While heritage signers can and do provide appropriate ASL instruction, and nuanced and authentic deaf culture experiences, heritage signers must understand that they have all the privileges of being a nondeaf person in academia and unpack how they are complicit in the systemic oppression of deaf people. As Linton writes, both disabled and nondisabled people can teach or produce scholarship in Disability Studies. Nondisabled people, however, "have a responsibility to engage consciously and deliberately with these [objectification, subjectivity, and absence of voice/presence] issues in their scholarship and teaching to avoid contributing to the problem" (Linton 1998, 152).

Finally, given that academia is an institutionally violent place for many deaf scholars, it is not surprising that there is a paucity of available deaf people who can teach ASL and deaf culture classes (Stapleton 2015; Woodcock, Rohan, and Campbell 2007). Nondeaf scholar of deaf culture, Lissa Stapleton (2015), identifies that deaf academics are constantly navigating and negotiating accommodations and spaces in academic environments. For example, accommodations for faculty are often from a separate funding, if such funds exist, than those for students (see Woodcock, Rohan, and Campbell 2007 for further explanation).

Rather than being broadly handled by a single entity, such as a disability services center, institutions vary in how they fund accommodations. Some require that the department who hired the deaf or hard of hearing faculty fund accommodations, which makes hiring those faculty prohibitively expensive. Deaf academics, who are already at a disadvantage compared to those who are nondeaf, additionally must convince colleges and universities that they are worth the extra expense (Stapleton 2015). This expense is compounded if deaf academics request a dedicated ASL interpreter. Dedicated interpreters are staff who tend to work solely with one deaf person, and can greatly assist in the recruitment, retention, and promotion of deaf faculty. Nevertheless, dedicated interpreters are an additional expense for departments that hire deaf faculty, and many interpreters acknowledge that they can earn more money freelancing than working as a dedicated interpreter.

Stapleton (2015) further explains that ASL faculty tend to be the only deaf professionals at universities. Spaces are therefore abled, and nondeaf. The lack of deaf representation can lead to what Kristen Jones et al. (2017) describe as subtle discrimination. Subtle discrimination, as explained by Jones et al (Jones et al 2017) is not conscious. It is unintentionally oppressive behavior that is reinforced by systemic

expectations of normalcy. Students seem to prefer building relationships with nondeaf faculty because they can converse without having to sign or use an interpreter. Other nondeaf faculty regularly go out to bars and restaurants together without inviting the deaf faculty because communication is too difficult. Deaf faculty may not always be called "doctor" even though they have a doctorate because of general expectations that any deaf faculty at a university *just* teach ASL. Through subtle discrimination, deaf faculty are isolated from their peers and from building viable and necessary academic relationships.

Colleges and universities who wish to offer Deaf Studies and ASL classes have an obligation to reflect upon the above-discussed social inequities that surround ASL and deaf people. As in the statement by the American Association of Colleges and Universities, we charge that "institutions should foster intellectual honesty, responsibility for society's moral health and for social justice, active participation as a citizen of a diverse democracy, discernment of the ethical consequences of decisions and action, and a deep understanding of one's self and respect for the complex identities of others, their histories and their cultures" (Mayhew and Fernández 2007, 55).

**How to Make This Right: Practicing Inclusion**

The first step for institutions to ameliorate years of profiting from the deaf community while at the same time creating barriers for deaf students and faculty, is to recognize the marginalization of ASL and deaf people. The next is to accord ASL the same respect given other languages and cultures. The teaching of ASL should satisfy the object of teaching foreign languages in liberal arts institutions and meet general education requirements in core areas, such as social studies, or global languages, which Daniel Yankelovich (2005) suggests is the promotion of translingual and transcultural competency. However, ASL holds possibilities beyond Yankelovich's translingual and transcultural competency. Finally, we must *crip the ASL classroom* and heed Linton's suggestions for developing Disability Studies. *Cripped* ASL classrooms foster student engagement with disability as not a problem but as "an issue, an idea, a metaphor, a phenomenon, a culture, and a construction "(Linton 1998, 134). To this end, how do we align the teaching of ASL with the Modern Language Association's (MLA 2007) assertion that there should be a "broad, intellectually driven approach to teaching language and culture in higher education?" (MLA 2007). The answer lies in extending authors Jan Kanda and Larry Fleischer's 1988 discussion of the question "Who is Qualified to Teach American Sign Language?," to consider how institutions can approach staffing, curricular design, and co-curricular activities in ASL programs with integrity. The discussion below intends to orient the readers to solutions available in current scholarship.

**Authentic Voices**

The object here is not specifically to argue what qualifies one to teach ASL but instead to advocate for authentic voices in ASL teaching. This is perhaps the most contentious arena for cripping the ASL classroom. Dirk Hillard (2017), the president of the Quad-Cities deaf club in Iowa, critiqued a college in the local press for offering ASL classes but not hiring deaf instructors to teach those classes (Hillard 2017). Hillard's suggestion that ASL programs should hire deaf, not nondeaf, instructors drew ire.

Hillard is far from alone in his opinion. Many deaf people believe the practice of hiring nondeaf people to teach ASL classes to be an act of cultural and economic appropriation (Lapiak n.d.). Deaf people frame this argument, grounded in disability justice, as "nothing about us without us," even as colleges scramble to satisfy demand for ASL classes. Nondeaf people substantially oppose this argument (Timpf 2017).

Placing deaf people in the classroom as the language teacher, model, and cultural authority offers students firsthand experience with transcending the boundaries between deaf and nondeaf, ability and disability. Deaf people's direct experience with a lifetime of navigating the world as non-hearing people adds a critical sensibility to teaching ASL and about the deaf experience.

This firsthand experience facilitated by authentic voices in the classroom brings students closer to an authentic encounter with deaf culture and organic use of signed language. In addition to Kanda and Fleischer's suggestion that the ideal ASL teacher has, "identifiable education and knowledge, along with certain skills and attitudes," we suggest that the ASL teacher is an individual with cultural competence and experience within deaf culture (Kanda and Fleischer 1988, 183). The teacher must be able to teach ASL in close relation to deaf cultures and in the context of the marginalization of signed language in American popular culture. While heritage signers (that is, nondeaf children of signing deaf parents) can meet all the requirements, we still emphasize that college and universities aiming to live by their missions of social justice should employ preferential hiring of deaf people. Deaf people in the classrooms serve as genuine conduits to local deaf communities, which can partner with the teaching classroom to provide opportunities for exposure to a wide range of language use, registers, and lived experiences. We furthermore argue that preferential hiring of deaf people does not constitute discrimination against nondeaf people, or "reverse audism" (see Eckert and Rowley 2013 for a discussion of audism). Rather, preferential hiring is a matter of corrective action in addressing economically marginalized deaf people. Beyond corrective action, colleges and universities should examine their inclusion practices to most effectively include deaf faculty within the institution, address implicit and explicit biases in hiring practices, and dismantle educational barriers that prevent deaf people from ascending higher education.

Offering ASL classes without considering those complexities and politics surrounding ASL and deaf communities contributes to the exploitation and marginalization of deaf people. Kanda and Fleischer, in their prescient 1988 piece, suggested that institutions "have an obligation to preserve the language and safeguard it from poor instruction and from those who do not respect its value as a language and the people who use it (Kanda and Fleischer 1988, 185-186)." This question persists three decades after the publication of their essay.

**Authentic Encounters**

Authentic voices entreat us to consider authentic encounters with those different from us and shifts one's own paradigm. How might we use ASL as a vehicle for teaching about the intersections of disability, difference, power, and social justice? Authentic encounters through the professor and through the texts, the curriculum, and co-curricular activities promote dialogue about disability justice, and reinforce the "nothing about us without us" sensibility. Deaf Studies scholar Dirksen Bauman (2004)

once suggested that the popularity of ASL classes would be a good opportunity to expose students to the concept of audism. By becoming aware of audism, students could then become more aware of their own microaggressions, of how they reproduce audist and ableist systems, and how they might become agents for a more just society. Learning about disability justice offers our students the opportunity to engage in conversations about other movements for social justice; and vice versa (Jarman and Kafer 2014).

Kanda and Fleischer suggest that good language teachers should have abilities to teach language while focusing on culture. Cultural awareness facilitates effective second language instruction (Kanda and Fleischer 1988, 186). Beyond tapping people on the shoulder and congregating in kitchens, what *is* deaf culture and what does it mean to teach ASL with a focus on culture? We argue that the ASL curriculum should situate language study in "cultural, historical, geographic, and cross-cultural frames within the context of humanistic learning" (MLA 2007).

The inclusion of a critical disability lens in the ASL program, through the incorporation of deaf and disability studies, extends the authentic encounter through critical engagement. To achieve this, deaf and disabled voices should be situated front and center. Deaf-centric materials are authored and produced by deaf people and focused on deaf cultural content: history, literature, rhetoric, and art. Deaf-centric material must be accompanied by mandated but carefully curated interactions with the community, and the use of deaf language models, or people who are fluent in the language but are not currently teaching it in the classroom. Scholarship by disabled people and from Disability Studies also contribute meaningfully to critical explorations of the place of deaf and disabled people in society. Well-designed collaboration with the local deaf and disabled communities for co-curricular learning can also be empowering for both the local communities and for students (See Fisher 2014 for further discussion of well-designed signed language based co-curricular programming). Collaborative co-curricular learning with local deaf and disabled communities with emancipatory attitudes produces critical encounters with disability and inequity for students to explore through discussion, collaboration, reflection, and interaction (Mayhew and Fernández 2007).

Students who take Disability Studies classes recognize that disability is a key aspect of human experience, and that disability has important political, social, and economic implications for society as a whole, including both disabled and non-disabled people. Most importantly, it allows able-bodied students to understand how they are complicit in a system which punishes deviations from normalcy and socially ideal bodies and minds (Schalk 2017). This framework of disability justice is necessary if institutions that offer ASL courses believe in their higher education missions and in the mission of language education, which is to foster cultural competence and globally engaged citizens. Perhaps of value is recognizing that disabled people compose a significant portion of our communities. Recent statistics suggest nearly one in five Americans have a disability (U.S. Census 2017). A critical approach to teaching ASL and Deaf Studies, considering its popularity, offers institutions an extraordinary opportunity to create a space for students to explore social justice and engage in sustained structural analysis of power dynamics. Encounters with disability and

disabled people in higher education prepares students to be engaged global citizens. Expanding spaces for authentic encounters outside the classroom through collaborative learning efforts with local deaf communities offer students the opportunity to gain translingual and transcultural knowledge (Fisher 2014). For example, community-based learning can include volunteering as coaches for a community-based children's sports teams with deaf participants, working with local deaf political advocacy organizations, or assisting with local deaf abuse survivors' agencies.

Collaborative learning becomes increasingly important as deaf cultural spaces dwindle out of existence due to social changes. Skyrocketing enrollment numbers for ASL classes far outpace the numbers of culturally identified deaf people and native users of ASL. With deaf spaces dwindling and the crunch of nondeaf "visitors" to limited deaf spaces, deaf activists are now actively resisting the customary practice of ASL teachers of sending students to deaf events for language immersion. They argue that nondeaf "visits" turn deaf events into spectacles of disability. Professors who require nondeaf "visits" for credit frequently resort to invasive methodologies to ensure that their nondeaf and able-bodied students actually are visiting deaf spaces, such as selfies with deaf citizens and presenters. Popular slogans among resistors and activists include "we are not your deaf field trip" and "we are not animals in a zoo." Community visits by nondeaf students for course credit is a sore point for deaf people, whose clubs and schools are closing or dwindling. Many deaf people increasingly rely upon temporary spaces such as deaf happy hour or deaf religious meetings for social opportunities, to converse fluently in their own language (thus giving ASL organic spaces to flourish), and to vent about living in a world that is made for nondeaf people. To continue sending students to deaf events for language immersion without collaboration with the local deaf communities can be considered an invasive act; that is, it shifts the purpose of deaf spaces to accommodate nondeaf needs. Alternatively, places trying to provide access to deaf people are often overrun when they hold ASL-accessible events. Nondeaf students of ASL dominate the spaces. For example, it is common for museum tour guides to be asked to sign more slowly during ASL tours for ASL students, depriving deaf patrons of full access and enjoyment of the tour.

Making this sort of behavior especially egregious is the fact that ASL accessibility is an ongoing struggle, as evidenced by Berkeley's refusal to provide interpreters for Barker. As well-known ASL educator, author, and poet Ella Mae Lentz (2011) said in her YouTube video, we owe the existence and beauty of ASL to the generations of deaf people who originated and grew the language (Lentz 2011). Therefore, it's important that educators consider carefully how they send nondeaf students into deaf spaces. To minimize negative repercussions for local deaf communities by nondeaf seeking authentic experiences, teachers of ASL and deaf culture who wish for their students to have language immersion experiences should work in collaboration with the local deaf communities to create emancipatory spaces for learning encounters to take place. Well-mediated encounters create spaces and moments where ASL and deaf culture students develop intuitive use of language and reflect on their applications of classroom learning. Solutions should come from local deaf communities themselves and signed language faculty are obligated to perform community outreach.

**Authentic Faculty**

As Mckay (1998) reminds us, finding suitable minority teachers to teach classes about their language, culture, and heritage can be difficult because systemic barriers and oppression makes attaining higher education challenging. Deaf education researchers Carrie Lou Garberoglio, Stephanie Cawthon, and Adam Sales (2017) report that deaf people typically have lower educational outcomes than comparable able-bodied people (Garberoglio et al. 2017). Only seven percent of the deaf population earn advanced degrees. These numbers further decrease if deafness is one of multiple disabilities (e.g. deafblind, deafdisabled) and for deaf people of color. The funding structure of colleges and universities sometimes do not allow for hiring faculty who do not have terminal degrees. This can inadvertently create situations where college and universities hire nondeaf people because of bureaucratic inertia. More social justice minded colleges and universities that prefer deaf professors often find that not every deaf graduate student or faculty member is interested in teaching ASL or deaf related content. However, because social justice minded colleges and universities are incentivized to have deaf professors, since doing so allows them to ethically profit from ASL and deaf culture classes, many deaf faculty and graduate students feel pressure to teach ASL and deaf related content. Both authors of this paper, a historian, and an applied linguist, report that they have at times been required to teach ASL, or felt pressure from administrators and peers to teach ASL and deaf related courses "because a deaf person should teach those classes, right?" Furthermore, fluency in signed language alone does not ensure pedagogical ability to teach a language well. The expectation that any deaf faculty or graduate students will teach ASL or deaf related content creates environments where the rarity of deaf scholars leads nondeaf staff and faculty to automatically assume that any deaf scholar is an ASL teacher. Such expectations and assumptions can be considered a form of microaggression.

Deaf scholars struggle to find employment in higher education outside ASL and Deaf Studies programs. In the rare cases where deaf faculty who do not teach ASL or deaf related content, but work alongside nondeaf faculty who do, those deaf faculty are often called upon to reassure their nondeaf colleagues that it is okay for them to teach ASL and Deaf Studies. Managing *nondeaf or able-bodied fragility*can be considered a form of emotional labor performed by deaf faculty for nondeaf colleagues. The concept of nondeaf or able-bodied fragility is inspired by Robin DiAngelo's (2011) *white fragility* and the notion of fragile masculinity from gender studies. DiAngelo defines white fragility as "a state in which even a minimum amount of racial stress becomes intolerable, triggering a range of defensive moves," (DiAngelo 2011, 57). She further explains that white people tend to be racially comfortable, which means that they often do not have to face racial conflict (DiAngelo 2011). White people find affirmative action and so-called political correctness threatening because they feel that they're being individually targeted.

The concept of fragility also extends to other types of intersectional scholarship. Fragility has been used by feminist scholars to examine the effects of patriarchy and toxic masculinity on cisnormative, heterosexual, male behavior, while recognizing the intersections of gender and race in shaping responses to challenges to one's privileges. Men, because of the privileges and expectations of their gender, also engage in

defensiveness when confronted about patriarchy, sexism, and gendered equity. The frequency of this occurrence on social media has led to a popular hashtag, #masculinitysofragile. Similarly, nondeaf or able-bodied people rarely find themselves fighting for accommodations or disability justice unless they themselves are temporarily or permanently disabled. When the deaf community points out that deaf people who want to teach ASL and Deaf Studies should have primacy over nondeaf people, nondeaf teachers of ASL and Deaf Studies feel threatened. As mentioned earlier, nondeaf teachers rely on deaf faculty for reassurance that their jobs are not at risk. "I'm a good teacher of ASL, aren't I," they ask the deaf faculty, "Should I quit my job? Do *you* want my job?". As Ayana Weekley (2012) explains, efforts by oppressor groups to align themselves with their oppressed counterparts reflect a desire to minimize intersectional conflict while benefiting themselves (Weekley 2012).

McKee and Woodward (2014) suggest that the best way to both foster social justice minded signed language and deaf culture education, and promote jobs and education in the deaf community, while minimizing the hiring of nondeaf faculty, is to train members of local deaf communities how to become signed language instructors. Colleges and universities can fund this training, both as an investment in individual deaf persons, and to ensure that their ASL and deaf culture classes are taught by competent deaf people. Because ASL classes are so profitable, supporting the education of future ASL teachers serves the interest of colleges and universities. However, this option does not confront inherent challenges in making lines of funding available for faculty with non-terminal degrees. It also requires that colleges and universities examine promotion tracks for those faculty who are hired only as instructors, adjuncts, or lecturers.

The problem of language instructors serving primarily as adjuncts or on the non-tenure-track is not unique to ASL. In language teaching, there is a two-tiered hierarchy where "literature professors are tenure-track and language instructors are often in non-tenure-track positions" (MLA 2007). Profiting off ASL while not actively seeking to employ deaf people or include them in the power structures of the university is unethical. We agree with the MLA that there needs to be a transformation of how languages are taught—not as a two-tiered structure but as a more coherent and cohesive curriculum. This applies to ASL: instead of seeing it as some language study followed by professional training in interpreting or deaf education, we should approach ASL as a more "continuous whole" with interdisciplinary appeal. This interdisciplinary appeal emphasizes ASL's place in the humanities and within the larger scope of a liberal arts education.

**Conclusion**

In the vein of scholar William Platter (2011), who wonders about the decisions that shape higher education's engagement with communities, we ask how those institutions engage with deaf and disabled communities when they offer signed language classes. We argue that any institution that has ASL and deaf culture classes must engage with deaf communities. Higher education institutions with a commitment to liberal education understand that their institutional mission depends on "the integrity of the curriculum…[which] requires integrity of the institution (Gaff and Meacham 2006). To this end, we argue that those institutions with an interest in

offering ASL classes should be invested in authentic voices, authentic faculty, and authentic encounters within and outside the ASL classroom. The absence of bona-fide deaf people from ASL programs—as teachers or as community partners—contributes to the "othering" of deaf people. That is, nondeaf students are not exposed to deaf people. However, this type of exposure is critical in recognizing the humanity of those who are not like us. To teach ASL without deaf linguistic models is to miss the opportunity to promote interaction across difference and serves as a form of erasure. The value of ethical decision making in implementing, administering, teaching ASL in higher education is to understand the impact of institutional actions on local communities, and on the lived experiences of deaf people who struggle because of cultural appropriation, economic discrimination, and linguistic marginalization. For example, ASL students may graduate from a signed language interpreter education program but remain dysfluent and absent the cultural competence to work as an effective interpreter. As Kanda and Fleischer (1988) suggest, teachers should respect the language [ASL] and its history. We argue institutions should too, through deliberative hiring and curricular decision-making.

As Mayhew and Fernandez (2007) point out, "embedded in the mission of U.S. Higher education is the ideal that colleges and universities are responsible for graduating students with the capacities and skills needed to be tolerant and responsible citizens in a diverse democracy" (Mayhew and Fernandez 2007, 76). Our challenge to administrators is that institutions work to remedy the wrongs visited upon deaf people to compensate for how they've profited from ASL coursework. Hire ASL teachers capable of engaging nondeaf students in the local deaf communities in socially responsible ways. Introduce students to Deaf Studies and Disability Studies scholarship. Encourage nondeaf students to encounter authentic deaf people and native users of ASL. Deliver a high-quality learning experience in ASL where students achieve true linguistic and cultural fluency and competency. Furthermore, we remind administrators that offering ASL and Deaf Studies courses to nondeaf people while actively denying deaf people full access to university courses and events, and not hiring deaf scholars to fill positions outside the deaf niche is the very essence of audism. Berkeley, which was used as an example of a university that refuses basic accommodations for its deaf students, has several levels of ASL courses, and deaf culture classes as well.

We do not intend to make the argument that ASL courses or Deaf Studies are the best way to expose nondeaf people to deaf experiences, nor that ASL or Deaf Studies courses are the best way to recruit deaf and disabled faculty. Rather, the popularity of ASL courses serves as an splendid vehicle for improving access, equity, and quality of life for deaf people (Bauman 2004) and by extension, encourage students to intellectually engage with disability. The absence of strong cultural content in an ASL course, and especially with a teacher not versed in authentic representations of deaf culture, contributes to the erasure of deaf culture and deaf experience in shaping the language and its existence in the 21st century. A well-designed ASL or Deaf Studies course presents the opportunity for students to learn about attitudes about languages, linguicism, linguistic inequities, nationalism, hegemony of English, ableism and the place of disability in American society, and the richness of deaf culture and deaf gain

(Bauman and Murray 2014). The social justice benefits of offering ASL and Deaf Studies encourage us to think about language as a human right, disability rights, access, and inclusion. The barriers surrounding ASL afford us the opportunities to discuss language attitudes in the United States, often centered on race and ethnicity, anti-bilingualism, and xenophobia. Those discussions allow students to develop and apply analytical tools to critique how disability is framed in the media. Applying the disability lens encourages students to think about how divergent bodies are othered and observe how society is structured to perpetuate cycles of structural inequity. ASL represents an opportunity to serve as a springboard for teaching social justice, disability justice, and as a bridge to Deaf and Disability Studies (Erevelles, 2000). But colleges and universities must first model what they want their students to learn by engaging with and exemplifying the principles of civic engagement and equity.

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# Contests for Meaning: Ableist Rhetoric in Video Games Backlash Culture

**Hayley R. Crooks**

**Abstract**

*An increasing number of video games focus on empathetic identification across difference. Since the mid-2000s, games that encourage catharsis and immersive engagement with trauma range from the personal as in That Dragon, Cancer (2014), in which players experience what it is like to parent a terminally ill child to geopolitical struggles as in Peacemaker (2007) which encourages player empathy for both sides of the Israeli-Palestinian Conflict. These games are rapidly gaining in popularity and commercial backing. As more games focus on issues of social justice, the backlash against these concerns among a vocal segment of the gaming community is increasing in frequency and intensity. A branch of the men's rights movement has focused on video games aimed at understanding difference, and has attracted attention suggesting that all those advocating for social justice in games (dubbed Social Justice Warriors) should be understood to have narcissistic personality disorder (NPD). We argue that these claims to NPD need to be understood as a form of structural ableism mobilized by the men's rights movement. In doing so, we argue that by situating the mental health labels evoked by current men's rights' activist rhetoric about feminist anti-racist interventions in game culture is a new form of the old practice of attaching mental health labels to people challenging social norms underpinning the dominant culture.*

**Keywords:** Gamer Culture, Ableism, Racism, Video Games, Misogyny, Feminist Game Studies

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Video game culture is changing and some gamers are very angry about it. There are an increasing number of scholars, developers, players, and game companies resisting the notion that the default gamer identity is a white, cisgender man. GamerGate (GG) is a violent movement that emerged as a backlash to progressive changes beginning to transform gamer culture. GG began as a personal attack against independent game designer Zoe Quinn. Quinn's game, aimed partially at teaching empathy and titled *Depression Quest*, attempts to demonstrate to players what it is like to live with depression. Quinn's game received positive reviews from mainstream game critics in forums including the widely read gaming publication *Rock, Paper, Shotgun.* Following the reviews, Quinn's abusive ex- boyfriend Eron Gonji claimed that *Kotaku's* Nathan Grayson (with whom Quinn was in a romantic relationship at the time) had given her game a positive review because of nepotism. While this claim was almost immediately disproven (Grayson had in fact never reviewed *Depression Quest*), the harassment and doxing 1 of Quinn and other women game designers was unleashed by gamers under the guise of championing 'ethics' in videogame journalism. The online harassment campaign occurred under the hashtag #GamerGate. In this way, a personal attack by an abusive ex-partner against one woman designer instigated what was widely referred to as "the most vicious online backlash against feminism in a generation" (Jason, 2015). Antifeminist actor Adam Baldwin launched the GG movement in 2014 when he used the hashtag #GamerGate in a sexualized, harassing Twitter post targeting Zoe Quinn (Kidd & Turner, 2016). Anonymous commenters and gamers enraged at the growing challenges being posed to a white male status quo in the gaming industry repeatedly used this hashtag to threaten, intimidate and demean advocates for social justice.

In this article, we analyze the ways that mental health labels were specifically deployed by proponents of GG to undermine feminist and antiracist activists intervening in mainstream game culture. Specifically, we locate the rhetoric mobilized by the GG movement against those they term 'social justice warriors' (a term used as a derogatory insult) within a broader historical trend of using ableist discourse to undermine the challenges posed by the intersection of women, people of colour and people with disabilities. In doing so, we aim to historicize the practice of using mental health labels to weaken those challenging systemic inequalities. Rather than a coincidence, the recurring references to mental health diagnoses in GG discourse is what disability studies scholars Mitchell and Snyder refer to as a "narrative prosthesis" (2000, p. 47). GG constructions of "social justice warriors" represent them as sick, with a particular emphasis on diagnosing them with Narcissistic Personality Disorder (NPD).

As more games center marginalized communities and inequality, the violent resistance to these concerns among a vocal segment of the (largely white and male) gaming community is increasing in frequency and intensity. The widely publicized harassment campaign that targets women and feminists now referred to as GG, and the paratexts surrounding it, form the basis for our case study. The GG movement began as a hashtag on Twitter and its members are active on platforms including Youtube, 4chan, 8chan and boards on Reddit such as Reddit's /r/ KotakuInAction (Massanari, 2017). 2 4chan—an anonymous forum that is described as "a simple image-based

bulletin board" on its website (www.4chan.org)—allows users to post images and comments without being identified. Reddit is a pseudo-anonymous news platform that allows users to post news items and vote to determine which stories end up on its front page. We by no means suggest collapsing the misogynistic language employed in public pseudo-anonymous networks online with instances of institutionally state-sanctioned violence against marginalized communities. And yet, detailing this history is important as the discourse of white supremacy perpetuated by GG proponents often has related consequences of violence for those targeted by these campaigns.

The most common label attributed to those concerned with the lack of diversity in games and digital culture — one that is particularly popular on men's rights activists (MRA) blogs and alt-right forums — is that those contesting white male gaming culture suffer from Narcissistic Personality Disorder (NPD) (Kelly, 2017). The term SJW, one that is used in order to undermine those fighting the intersections of racism, ableism and sexism online and in the gaming world, is increasingly a term applied to social justice advocates that come to be accepted in mainstream news outlets. 3 As hate mobs utter a seemingly endless stream of death and rape threats it is increasingly difficult for female, queer, and racialized individuals as well as those that identify as socially progressive to exist in gaming spaces and communities or to express viewpoints online even when being active online is a central part of their profession — as in the case of both journalists and game designers (Solon, 2016, paragraph 7). We briefly examine the history of how mental health labels have historically been used to discourage resistance to oppression before delving into our case study investigating the ways that NPD is used by proponents of the GG movement to label those fighting oppression in video games and gaming culture. From Adrienne Rich's description of how lesbians were labelled mentally ill and incarcerated in psychiatric institutions in an attempt to compel them to be heterosexual (1980) to the labelling of slaves with the psychiatric designation drapetomania (a mental illness stemming from scientific racism described as an illness causing slaves to want to flee enslavement), we show that the language of disability and psychiatry mobilized by GG is not new.

While the field of game studies has moved well beyond the much-rehashed debate between ludology and narratology, the field is still lacking in scholarship that poses diverse alternatives to preoccupations with either formal or representational concerns (Frasca, 2003; Eskelinen, 2001; Juul, 2011). 4 Building on the body of feminist and queer theoretical writings on video games offers a way to contribute to the field of disability game studies (Nakamura & Chow-White, 2013; Ruberg, 2015; Shaw, 2013; Chess & Shaw, 2015). This has become particularly urgent considering the events of GG and the rise of the so-called 'alt right media'. Feminist theory allows us to move beyond solely approaching games as media objects and instead opens a space to tackle the social and discursive practices that circulate around videogames. Our particular emphasis is on the ableist rhetoric that targets game critics focused on social justice. 5

The dominant narrative that has emerged from GG is simple: feminists, people who do not fit the gender binary, racialized individuals and social activists are ruining videogames (Chess & Shaw, 2015; Massanari, 2017; Wingfield, 2014). Sadly, this conflation of a social justice critique with women and feminists 'ruining' not just games

but public spaces on the internet is widespread, particularly in social media. It is also becoming rapidly normalized as we saw in the appointment of Stephen "Steve" Bannon of *Breitbart News* as (now former) chief White House strategist for Donald Trump's administration (Marantz, 2016). Breitbart published a piece suggesting that the solution to the harassment (which he placed in scare quotes) of women online is for women to "log off" (Milo, 2016). Here, we instead focus not on either separating "a videogame's components into distinct spheres" or focusing on representations within games but suggest that we must take a closer look at the toxic elements of game culture itself (Massanari, 2017). Posing the following questions about GG and toxic game culture, we ask: how do the discursive practices of GG construct and define game culture? What is the relationship between GG rhetoric and broader forms of ableist misogyny online? What do alt-right and men's rights targeting of empathy games tell us about the relationship between GG and broader alt-right movements?

We are interested in analyzing how game culture "feeling rules" (Hochschild, 1979 [2005]) as well as the formal rules of the games themselves "come together during play to be embodied by and incorporated with the player" (Keogh, 2014: 7). In documenting the "contests for meaning" (Haraway, 1992) over what constitutes acceptable emotion in relationship to video games, we document that the misogyny and racism spawned by predominantly young white male gamers defending mainstream videogames is not only a political battle or a battle over resources but also an *affective* struggle. The term affect until recently has been most commonly associated with its use in the field of Psychology to refer to an experience, feeling or emotion and is used to describe an organism's interaction with stimuli (APA 2006). Since the affective turn in Feminist Theory and Cultural Studies, affect theory is now broadly used and applied by scholars across many fields to interrogate issues such as the political nature of emotion (Ahmed, 2004; Berlant, 2011) and the role of the body in social theory (Franklin, 2007). Video games scholar Aubrey Anable argues that video games are places where individuals try on feelings. Rather than an escape from reality, game spaces are thus bound up in existing emotional landscapes (2018). Anable's work offers a productive way to understand the hate campaign launched by GG as bound up in a form of "Internet eugenics" (Schwartz, 2012 quoted in Anable) that undermines the potential for equitable forms of agency for (techno)subjects in digital culture (Anable, 2008). GG rhetoric is markedly bound up with broader discursive practices online that are 'mainstreaming' the notion that social justice critics—particularly those doing feminist and anti-racist work—do not belong in online spaces.

**Empathy Games and Affective Labour**

Since the development of the first videogame *Pong* (1972) more than forty years ago (Perez Lattore, 2015), which consisted of a universe made up only of circles and lines, videogames have increased significantly in complexity. Although first person shooters and violent imagery dominate the industry, several independent game developers are designing games referred to collectively as 'empathy games' in which they attempt to build prosocial dynamics into game play (Harrington & O'Connell, 2016). 6 For example, in games such as *Super Mario Crossing* and *Zoo Vet* the player must help and cooperate to succeed (Harrington & O'Connell, 2016, p. 650). Since the mid-2000s, games that encourage catharsis and immersed engagement with trauma

ranging from the personal as in *That Dragon, Cancer*(2014), in which players experience what it is like to parent a terminally ill child, to geopolitical struggles as in *Peacemaker* (2007) which encourages player empathy for both sides of the Israeli-Palestinian Conflict. These games are rapidly gaining in popularity and commercial backing. For example, in 2012 Sony funded the Montreal indie studio "Minority" in their game *Papa & Yo* that allows the player to navigate life with an abusive and alcoholic parent (Wells, 2016). The link between the backlash against empathy games (often manifested as anger over the ontology of games —e.g., games are not meant to engage with these issues) and the misogynistic discursive practise of GG that positions women (and minority groups) as the "enemies" of games within game culture inform this article.

Video games engage as affectively (Anable, 2018). In one of the most oft-cited examples of misogyny in video games, in *Grand Theft Auto 3* (and onwards), a player's character's health increases (they receive "life points") when they have sex with sex workers as part of gameplay. The fifth incarnation of *Grand Theft Auto*remains the fastest entertainment product to gross $1 billion—which it did in a mere three days (Rodenberg, 2013). Although you must pay the sex workers initially, the game allows you to murder these women and then take back the money. In this way, the structure of the game encourages players to engage in a persona who takes pleasure in taking part in acts of violence against women. Protagonists also must engage in other forms of violence to succeed in the game, from gang warfare to torturing informants to get the information required to play the game. 7 From sympathetic identification with game protagonists to frustration when a player fails to win the game, videogames are centrally concerned with producing emotional responses in players (Anable, 2018; Richard, 2015). And yet, while certain emotional responses are understood as acceptable in relationship to videogames (pleasure in beating your opponent, pain when your character dies), other forms of affective expressions are represented as narcissistic (pleasure in feminist analysis of what is lacking from a game, pain at systemic discrimination during gameplay). That is, what counts as 'proper' affective alignment or labour is central to ongoing feminist debates about videogames. These "contests for meaning" (Haraway, 1992) as to the affective nature of videogames offer context for the ways that GG violence is symptomatic of a broader structural problem in mainstream gaming culture. Here, further context aimed at unpacking affective labour is helpful to our analysis. In her groundbreaking work *The Managed Heart*(2005 [1979]), sociologist Arlie Hochschild invented the phrases "emotional labor" and "feeling rules" to describe a category of work that had formerly been invisible: that in which people are compelled to use their emotions as part of their jobs. In her words, emotional labor involves the "management of feeling to create a publicly observable facial and bodily display" and it "requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others . […] This kind of labor calls for a coordination of mind and feeling, and it sometimes draws on a source of self that we honor as deep and integral to our individuality" (2005 [1979]: 7). Describing the work done by labourers from diplomats to flight attendants, Hochschild argues that people are increasingly estranged from their actual emotions as

they are compelled to perform acceptable displays of servility, strength and compassion for pay.

More than three decades of research into emotional labour has built upon Hochschild's work. Hardt and Negri's (2000) analysis of the contemporary shift to an economy fueled by "immaterial labor" (including emotional and digital labour) from an economy based on the production of material goods documents the affective impact of the transformation of contemporary North American society to economies centered on information (2000: 290). Johanna Oksala adds to Hardt and Negri's analysis of emotional labour in her article "Affective Labor and Feminist Politics" (2016), arguing that we need to complicate the phrase emotional labour to consider the different types of this form of work. For example, it is problematic to consider the provision of compassionate health care as identical to the affective labour done during the carrying of a surrogate baby. That is, while health care work can result in compassion fatigue and an estrangement from one's own emotions, the care work of surrogacy can be life-threatening as the drugs that surrogates are likely to be asked to take can have devastating health consequences (DasGupta and Dasgupta, 2015). That is, while we might want to problematize both kinds of emotional labour, they take different forms and have different implications for those who perform them. In addition, since the publication of Hochschild's book, the ways that affective labour is gendered, racialized and classed has been further theorized (Oksala, 2016; Cvetcovich, 2012; Ahmed, 2013). More specifically, feminist theorists are paying increased attention to the ways that emotional labour is disproportionately done by "women from subordinated racial-ethnic minorities in most Western countries" (Oksala, 2016). Oksala's call for a typology of affective labour is extremely helpful in that a form of affective labour—one that involves explaining existing forms of ableism, sexism, and racism to outsiders—falls onto the shoulders of feminist critics of videogames, disproportionately composed of queer folks, people of colour, women, people with disabilities and those at the intersection of these categories. Below, we document the ways that we continue to see this gendered and racialized distribution of emotional labour being done by feminist video game critics including those increasingly targeted by those wishing to police the traditional boundaries of gamer identity play including the extreme end of the backlash represented by GG.

**Historicizing Feminist Conflicts Concerning Video Games**

While the mainstream awareness of harassment against women in the gaming industry has only recently garnered significant press coverage, the number of violent threats against women developers has risen dramatically in the last few years (Berlatsky, 2014; Chess et al., 2014; Chess & Shaw, 2015; Hathaway, 2014; Hess, 2014), including the death and rape threat campaigns that were launched against video game developers Brianna Wu and Zoe Quinn as well as against feminist media critic Anita Sarkeesian. And yet, this is not the first moment that feminists and other social justice advocates inside and outside of gaming have been in conflict with the video game industry. Occurrences of misogynistic and racist harassment in gaming are ongoing and well-documented (Chess, 2014; Consalvo, 2012; Huntemann, 2013; Shaw, Stabile & Stromer-Galley, 2014). Although many still think of game studies only in terms of the branch that grew out of computer science and communication studies (Egenfeldt-

Nielsen, Smith & Tosca, 2016), there is a long precedent within academic game studies of bringing a social justice lens to issues in the gaming industry. For instance, while the first text widely recognized to be part of the field of feminist game studies text did not appear until Cassell and Jenkins' edited collection *From Barbie to Mortal Kombat*(2000), the first generation of feminist game studies scholars began by building on the work of Janet Murray (1997), Sherry Turkle (1995) and Brenda Laurel (2001)—carving out a respected body of work amid the machismo of game studies (Kirkland, 2005). Moreover, feminist and queer game scholars (Gajjala, 2013; Nakamura, 2002; 2008; 2012; Ruberg & Shaw, 2017) have modeled ways to shift the focus from ludology and the rules of the game to the ways that games may further entrench systemic forms of discrimination — showing that this intensification is neither natural nor inevitable.

Similar to the ludology vs. narratology debates, the question "what is a gamer?" (Huntemann, 2013) has been central to game studies since its inception as a critical field of study drawing on work from computer science, anthropology, psychology, arts and literature (Jones, 2008). Scholars invested in game studies argue about everything from whether social science methods should be used to measure the impact of games on human beings (Ferguson 2010; Gerber & Price, 2011) to whether games can be properly analyzed using the techniques developed in media studies (Jenkins and Thorburn, 2003). Drawing from the tools of feminist, queer and women of colour critiques of video games studies and culture offer useful ways of understanding how the video game industry and market forces produces a 'natural' gamer identity that is presumed to be male and coded through hegemonic—white, male, (cis)gendered and able bodied — masculinity (Engel, 2017; Malkowski & Russworm, 2017; Ruberg & Shaw, 2017; Shaw, 2015). The recent rage that we have seen expressed in gamer culture "seems to be based on at least two factors: sexist [as well as racist, homophobic and ableist] beliefs about the abilities and proper place of female [racialized, queer] players and fears about the changing nature of the game industry" (Consalvo, 2012). The concept of "narrative prosthesis" (Mitchell & Snyder, 2000) is useful in analyzing the ableist affective rhetoric deployed by GG in their rage against those they refer to as SJWs. That is, GG comment threads and posts continually diagnose those who do not agree with them as having Narcissistic Personality Disorder (NPD) and other mental health issues in a logic that equates social justice with disability: those within the gaming community that advocate for inclusion and systemic change are therefore represented as deviating from normative, white masculinity.

As Chess, Consalvo, Huntemann, Shaw and Stromer-Galley (2014) argue, while the events of GG may seem new, they are actually a continuation of the vicious harassment and outright threats directed towards marginalized individuals critical of the systemically oppressive climate in game development and culture. Numerous incidents reveal the long running tensions between women, feminists and commercial games and there are many moments of rupture when women/people of colour invested in gaming either as players or developers call out the hegemonic power relations normalized through misogyny and racism in the industry. For example, in 2010, Mike Krahulik, who is the cartoonist behind the webcomic Penny Arcade, posted a comic strip involving a character who is raped by "Dickwolves." After an outcry from activists and rape survivors, Krahulik still went on to create merchandise such as t-

shirts with "Dickwolves" printed on them that sold at major gaming conventions, and announced at the major gaming expo Penny Arcade Expo (PAX) that "the merchandise had been created as a "'screw you' to rape survivors who had the temerity to complain about a comic strip" (Edidin, 2013). Although the systemic violence towards people of colour/women/queer people/people with disabilities from the gaming community has a long history (Consalvo, 2013), these conflicts came to a head in GG. This conflict was primarily represented in the media as being between two communities: GG proponents and so-called SJWs. GGrs purport to be a group committed to maintaining ethics in games journalism, however, GG is accurately described by Vist as a "concerted harassment campaign masquerading as a consumer protest" (2015: 57). 8Following video game theorists Andrea Braithwaite (2016), Elise Vist (2015) as well as Shira Chess and Adrienne Shaw (2015), we understand GG as a backlash movement or public launched by gamers who believe that mainstream gaming culture is "threatened by and hostile to games and players who question the supremacy of first person shooters, white male leads, and the assumption of heterosexuality" (2015: 65). We have seen this backlash— frequently carried out through pathologizing ableist rhetoric—increase as independent studios as well as mainstream games have begun to expand the communities represented in games as they begin to recognize the plurality of folks who identify as gamers (Burgess & Matamoros-Fernández, 2016; Massanari, 2017). While GG supporters mean to use the term SJW to demean those who dare to stand up to misogyny and racism in video games, we follow Vist in understanding those labelled as SJWs as a community of "people who believe that there is room for feminist critiques, race awareness, and social activism in games" (2015: 59). Furthermore, we suggest that social justice activists embrace the term SJW as it is only since 2011, when the term was re-branded by GG proponents through a Twitter hashtag, that the term is used pejoratively in popular parlance.

If you include casual games, women make up 74% of gamers (Casual Games Market Report, 2007). Given this statistic, how does hegemonic maleness continue to dominate the videogame industry? Casual games include digital puzzles, word games and card games and generally have simple graphics, require only a short time commitment at any playing and are available for a minimal cost or are free. Although the industry and majority of critics claim to dismiss casual games due to their minimalist aesthetic and easy-to-navigate structure, casual games are clearly also dismissed because of the high number of women who play them (Anable, 2013; Vanderhoef, 2013), and, thus, the emotional pleasures players find in these games are disregarded (Huntemann, 2013). That is, the boundary policing of games (e.g., first person shooter and strategy games are 'real'/'good' games) is gendered (Anable, 2013). Feminist/anti-racist critics working in the game industry or in game studies have continually attempted to broaden the categories of what counts as a video game (largely normalized as linear and success-based). For example, Maureen Engel (2017) developed the mechanic for her prototype game Go Queer around the "principle of queer play" rather than game play to challenge the social and political norms that currently structure game mechanics (2017: 352). Despite feminist interventions, what is understood to count as a game remains deeply contested. For example, Anna Anthropy created the game *Dys4ia* (2012) to immerse gamers in the frustration and

complexity of a trans woman's experiences of trying to gain access to healthcare and hormone therapy within normative gendered contexts of stigma (Kuchera, 2012). Although many conventional gaming rules structure *Dys4ia*, the player is set up to fail in many instances, unlike in mainstream games, offering an opportunity to experience these specific frustrations. Elise Vist (2015) notes that even non-hostile reactions to *Dys4ia*suggest that the maker of this game should have posted it as an "art" game rather than as a mainstream game.

**Using Disability to Police Resistance: Historical (Institutional) Perspectives**

The use of disability in order to undermine those vocalizing resistance to normative societal structures has a long history. In Adrienne Rich's foundational essay "Compulsory Heterosexuality and Lesbian Existence," Rich describes how lesbian women were labelled mentally ill and then coerced into psychiatric institutions where they were forcibly subjected to "corrective" rape. For example, Rich cites the case of an Oslo woman who was in a heterosexual marriage in which she was deeply unhappy. She began taking tranquilizers and ultimately "ended up at the health sanatorium for treatment and rehabilitation" (Russell and van de Ven cited in Rich, 1980: 653). During her time at the sanatorium, she asserted that she was a lesbian. At this point, she was incarcerated under the guise that she was mentally ill and sentenced to six months of "corrective" rape by her husband. Here, Rich demonstrates how the label of mental illness was used to undermine the resistance (and threat) that lesbianism poses to a heteronormative social order while it simultaneously facilitated institutionalized violence against queer people. We do not suggest that GG's harassment and eugenic rhetoric directed toward feminists and social activists is the same as historical forms of institutionalized violence and discipline. And yet, looking to a historical context rife with the violent institutionalization and oppression of queer women and people of colour helps us to better understand the stakes of the discourses used to construct GG. Moreover, social media scholars are beginning to recognize and document the increasingly normalized death and rape threats directed at feminists and anti-racist activists that are proliferating in gaming culture as well as in digital culture more broadly (Banet-Weiser & Miltner, 2016; Rubin, 2016). This emerging literature points to the urgency of addressing the sexist racism that is not only attached to a dismissal of indie games that privilege connection and empathy (as opposed to winning and exclusion), but also, the very presence of individuals advocating for social justice concerns in mainstream game culture.

The queer community is not the only community that has been subject to pathologizing labels — ones that reflect what we have been referring to as an affective rhetoric of ableism—wielded in order to suppress challenges to the dominant order. Diagnoses of mental illness have also long been used to police people of colour's resistance to white supremacy. During the 1850s, drapetomania was a label used by psychiatrists to describe a supposed mental health condition that made slaves want to flee their captors (Metzl, 2009: ix). More recently, Jonathan Metzl (2009) has documented how various forms of mental illness have consistently been used to label people of colour's struggles with racism as disordered. As he notes, prior to the Civil Rights movement, schizophrenic patients were assumed to be largely white, and were

understood as "generally harmless to society" (2009: xii). Following people of colour's demands for an end to racism in the 1960s, Metzl documents how the diagnosis of schizophrenia began to be disproportionately applied to Black people at the same time as it came to signify the most dangerous mental health disorder. Metzl shows how this diagnosis (given to black men at four times the rate of white men following the Civil Rights movement) continues to be used to justify the incarceration of an untold number of African Americans in institutions from psychiatric facilities to the prison industrial complex (Alexander, 2010). It is critical that we remember the fundamental distinctions between institutionalized and legalized oppression, and yet, these historical examples of institutionalized violence shed light on the ways that diagnostic terms have mobilized ableist affect and been deployed in attempts to silence people challenging hegemonic power structures. In other words, placing GG's rhetoric in historical context from Rich's compulsory heterosexuality to drapetomania underscores how (old) interlocking logics of ableism, sexism and racism persist in the (new) 'culture wars' occurring digital culture. As we will see the terminology and rhetorical strategies employed in GG operate within a broader context of oppression and work to normalize the notion that feminists are ruining games for the real gamers (white, middle-aged, cis-gendered men).

**Case Study: Affective policing and Video Games**

In her close readings of *Dys4ia* (2012) and *Gone Home* (2013), Elise Vist (2015) argues that games aimed at fostering empathy can be disorienting to their players. 9 Drawing on Sara Ahmed's phenomenological theory of dis/orientation, Vist argues that players whose bodies fit normatively within hegemonic spaces expect "to be orientated towards the objects in their reach" (2015: 58). As Vist reminds us, although not real-world spaces, games have avatars and cyberspaces to which we become accustomed. These new game spaces thus permit for new forms of dis/orientation. That is, "When a subject who has always understood the world to center around themselves is placed in a space that refuses that centrality, they must find their way again. They must re-orient themselves. Rather than reaching out to find familiar objects in expected places, they reach out to find that there is nothing where they expected something (or something where they expected nothing)" (Ahmed, 2006: 11 cited in Vist 2015: 59). The hateful and ableist rhetoric of GG does not exist in a vacuum and is rooted in a broader gaming culture that is slow to change when it comes to who is considered a 'real' gamer, which games are considered 'real' games and what it means to have fun. That is, why does a game have to be hegemonically 'fun' to be a game? What is often framed by gamers as a desire to keep politics out of games is a way of maintaining a white, heteronormative gamer identity (Braithwaite, 2016; Condis, 2014). For example, in her study of fans' reactions to BioWare's addition of the option of playing as a gay male character in *Star Wars: The Old Republic* (2011) and *Dragon Age II* (2011), Megan Condis (2014) found that the backlash resulted in a reinforcement of the gendered, racialized, sexualized and classed boundaries of gamer and fan identities. It important to note that the disorientation produced by empathy games can be both productive and pleasurable (Vist, 2013): it can give the player a chance to think about what it means to feel out of place as well as a chance to reflect on how privilege might structure who feels they belong and who feels excluded from an

environment (whether virtual or real). And yet, it is precisely this moment of disorientation that causes many players to express rage. That is, in response to games that do not make them feel comfortable or that are specifically aimed at making them feel out of place, many players express hostility because they do not find the game fun (as in the case of *Depression Quest*), or because the game is not a 'traditional' game (as in the case of *Dys4ia*), or because the game's creator belongs to a hated political community (including feminists, people of colour, queer people, et cetera). Of course, *Depression Quest* purposefully creates an affective disorientation for the player who is placed inside the protagonist's struggle with depression. GG's reactions of rage seem disproportionate to the experience of not finding a game enjoyable. We next use Robin DiAngelo's concept of "white fragility" (2011) to further unpack gamers' affective reactions to empathy games as well as their designers and players.

Arguing that white people in North America live in an environment that "protects and insulates them from race-based stress" (2011: 54), DiAngelo demonstrates that this protective cocoon results in white people having high expectations of "racial comfort" and a low tolerance for racial embarrassment. These expectations of racial comfort lead them—when they experience even a small amount of discomfort because of their privilege—to display an affective range of emotions that include rage and violent hostility and to engage in "behaviors such as argumentation, silence, and leaving the stress-inducing situation. These behaviors, in turn, function to reinstate white racial equilibrium" (Diangelo, 2011: 54). We extend white fragility here to include other markers of privilege that result in male, heterosexual, and able-bodied fragility. Certainly, with respect to videogames, we see many of these behaviours occurring, as those hostile toward empathy games engage in both affective and real-life forms of policing of those who play empathy games or who want to add a feminist critique of commercial games. As we documented above, the harassment and intimidation of women and girls has accelerated in game spaces. Only 5% of mainstream videogames' protagonists are women and the hegemonic gamer identity is predominantly a white, heterosexual, cis-gendered, able-bodied man (Prebble, 2014). While change is slowly beginning to take place (one example is the blog and movement *Plz Diversify Your Panel* in which many prominent figures in gaming have added their name to a list stating that they will not participate in panels that only consist of "straight white dudes"), the major events including the Game Developers Conference (GDC) and trade shows (which continue to feature "booth babes" to sell games) continue to normalize misogyny and devalue games, mechanics and affects that are aligned with the feminine. The Twitter archive #1ReasonWhy offers a space for women to document the daily struggles they face in the gaming industry.

We combine DiAngelo's notion of the affective impacts of white fragility with the ableist expression of this rage that we see with respect to videogames. In particular, we note that a consistently reoccurring trope for how rage toward feminist or social justice critiques of mainstream games is expressed is through ableist language that argues that people waging critiques of these games must have a mental illness, specifically, Narcissistic Personality Disorder. Before proceeding to our case study of the use of the charge of personality disorders in the context of videogames, we would

like to review the history of how charges of mental health disabilities have historically been used to police resistance to oppression.

**Toxic Gamer Culture: The use(s) of Mental Health labels in the Normalizing of Racism & Misogyny in GamerGate discourse**

The pejorative term SJW used in GG rhetoric to champions of greater diversity in gaming, as well as to games scholars interested in gender, race and their intersections, might be productively re-appropriated by feminist disability game scholars. 10 SJW as a label speaks volumes about the emotional labour required by those working for greater diversity in gaming as demonstrated by ongoing work in feminist and queer game studies — both the labour required to advance a social justice critique as well as the labour required in defending themselves every day from personal, hateful attacks (Chess et al., 2015). For example, it is well-documented that feminist game scholars blazing a trail in this area are surveilled and targeted by GG (Chess & Shaw, 2015, 2016; Todd, 2015). As Leigh Alexander argues, the fight for social justice in games and the resulting massive backlash has somehow been rationalized as a "debate" — as if there could be two reasonable sides as to whether we have a need for greater inclusiveness and less harassment in the videogame world (2014). Although the term SJW is circulated as a criticism by proponents of GG, it also emphasizes the effort that is being put in by many individuals and (particularly independent) game studios to make games and their representations more inclusive. The term SJW could easily be used to describe the emotional labour that is required to simply *be* a woman, a person of colour, or a queer player given the culture in the gaming world. The affective labour central to naming oppression in game spaces and within the industry writ large continues to fall on the shoulders of the individuals — whether they are developers or gamers—who belong to oppressed and marginalized groups. After the events surrounding GG, when academics studying feminist criticism of toxic gamer culture themselves became the targets of GG vitriol, the emotional burden placed on gamers from oppressed groups came into focus. This is evidenced by the fact that academics that focus on racism, sexism, homophobia and transphobia in games and game culture are now regularly harassed online. As videogame theorist Mia Consalvo reminds us in her recent challenge to feminist scholars and their allies to take these threats and harassment seriously: "women, people of colour, LGBTQ scholars, indeed all scholars who are members of marginalized groups, have historically paid a disproportionate price when they engage in public scholarship, social justice advocacy, and political activity" (2014). While it is by no means a new tactic, pro-GG comments from gamers and game critics have employed everything from charging their critics with irrationality and mental illness to organized campaigns of targeted hate propaganda. All of these can become forms of emotional abuse and violence.

We noted above that mental health labels have often been used to discredit those who critique oppressive power structures. Unsurprisingly, this has been a key rhetorical and affective strategy employed in anonymous and pseudo-anonymous bulletin boards devoted to GG such as those on Reddit and 4chan as well as on the social networking platform Twitter. In hateful online communities dedicated explicitly to discrediting and demeaning feminists and activists critical of games, posts routinely tie Narcissistic Personality Disorder (NPD) to feminist activists. A diagnosis of

Narcissistic Personality Disorder (NPD) as defined in the DSM-5 requires the presence of a combination of "impairments" regarding both "self-functioning" and "interpersonal functioning" as characterized by traits such as "a grandiose sense of self-importance", "attention seeking" a belief that one is "special", and "a lack of empathy" (American Psychiatry Association, 2012). For example, a blog post on the misogynistic anti-feminist website "Return of Kings" states:

Social justice wankers are characterized by their narcissistic personality disorder. They get mutual validation and reinforcement from other SJWs. They have a hive mind mentality enforced by sessions of groupthink. The majority of these people show disturbing signs of narcissistic personality disorder—anything said is reinterpreted as accusation and attack on them, those accusations are instantly reflected back at the accuser, they are incapable of assuming responsibility for their own actions or their situation, they see themselves as morally perfect, they constantly redefine and invent dismissive language and rhetoric to suit their agenda, and they always underline how they are being unjustly persecuted.

Although the original post (originally published in Penny Arcade and SomethingAwful forums before appearing on 4chan) about Zoe Quinn was written by one individual, its rhetoric reflects misogynistic tropes used widely in alt-right forums such as the blog "Return of Kings" to discredit women developers. The homepage of the blog "Return of Kings" that markets itself as being for "a small but vocal collection of men in America today who believe men should be masculine and women should be feminine" states that "women and homosexuals are strongly discouraged from commenting". Among the community's stated central beliefs is that "socialism, feminism, cultural Marxism and social justice warriorism aim to destroy the family unit, decrease the fertility rate, and impoverish the state through large welfare entitlements" (ROK, 2016). While the hate mob that was mobilized through Gonji's post continues to result in a daily barrage of violent threats for Quinn, it also called on linguistic and affective strategies commonplace in daily gamer culture. For example, As Arthur Chu explained to *Boston Magazine*, "the 'crazy bitch' story" employed by Gonji in his infamous post in which he attempted to threaten and destroy Quinn's life (personal and professional) […is] a very potent trope to use, it's a very nasty, very calculating train of thought, and it worked" (Chu qtd in Jason, 2015). Of course, we would also note that it also mobilizes the language of sexist ableism ("crazy bitch") to discredit Quinn. One of the most popular strategies used to defame Quinn and her work by posters on such as Reddit is to undermine her work by claiming that her viewpoints and advocacy are structured by Borderline Personality Disorder (BPD) or Narcissistic Personality Disorder (NPD)—the clinical diagnosis too often ascribed to women developers, feminists and activists who work from a social justice perspective. That is, in many men's rights movement (MRM) websites sympathetic to #GG, Quinn and others are routinely 'diagnosed' with personality disorders. For example, on the website "A Voice for Men" one blogger Vincent James writes:

So why is all this happening? Why are all these game journalists silencing dissent on Zoe Quinn's behalf? In part 2 of the series, I will look into the political affilitations (sic) of her cronies and show evidence that much of game journalism today is dominated by feminist cliques, by fraudulent "social justice warriors" who have

transformed what was once an enjoyable pursuit into an ideological minefield. The chatlog portrays her to be a woman who cheats on her lover on a whim, who engages in reckless activities such as unprotected sex with multiple partners and drinking excessively, and who performs suicidal gestures to keep her from being (rightly) abandoned by her cheated-on lover. These are characteristic traits of Borderline Personality Disorder, a well-documented psychiatric disorder and part of the infamous Cluster B Disorders that abusive individuals usually possess. (http://www.avoiceformen.com/feminism/cronyism-lies-and-censorship-what-zoe-quinn-and-feminism-bring-to-gaming-part-1/)

American game developer Brianna Wu has also stated that "GG has ruined my life" (Jason, 2015). In October 2014, Wu, who co-founded the independent video game development studio Giant SpaceKat, posted comments critical of GG. Within moments she began receiving specific rape and death threats containing her home address and was driven from her home fearing for her life (Hart, 2014). Wu now deals with law enforcement at least once a day and can only attend events with a security detail. Anita Sarkeesian had to cancel a talk at Utah State University after the school received a threat in the form of a letter from an anonymous person that was sent to University staffers and published in USU's newspaper. The letter writer claimed to be a student at the university and declared admiration for the man who targeted and killed 14 female engineering students in 1989 at École Polytechnique in Montreal, Quebec after yelling "I hate women…you're all a bunch of fucking feminists" (Kowaleski-Wallace, 2009, p. 28). 11 The person threatened the "deadliest school shooting in American history" (CTV, 2014). Sarkeesian cancelled the talk after learning that due to Utah's "conceal carry law," despite the death threats against her, the university would not ban concealed weapons at her talk.

At their most benign, pro-GGrs claim that all individuals and journalists calling out misogyny and racism in games and calling for greater diversity are "espous[ing] demonstrably false opinions for attention" (Alexander, 2014). At their worst, individual and hate mobs threaten and incite (often sexual) violence against feminist social justice advocates courageous enough to speak out (Alexander, 2014). The most egregious examples of way that GG mobilizes ableist rhetoric to target 'SJWs' can be found in the original threat against Zoe Quinn that was posted to the anonymous discussion board 4chan in August of 2014: "Next time she shows up at a conference we…give her a crippling injury that's never going to fully heal…a good solid injury to the knees. I'd say a brain damage but we don't want to make it so she ends up too retarded to fear us" (anonymous post quoted in Parkin, 2014).

If GG has any silver lining, it is that it has shone a light on the degree of violence directed at women/queer people/people of colour in gaming. GG also highlighted the ways that the rhetoric itself demonstrates a reliance on ableist tropes that deploy mental health labels as a strategy to undermine a growing resistance to racism and sexism in games and game culture. The issue of harassment against women in gaming has reached the mainstream consciousness and is now often covered in major media outlets such as the *New York Times* (Ito, 2015; Wingfield 2014). Moreover, GG revealed the extent to which the economic and cultural hegemony of 'traditional' gaming is dwindling (Alexander, 2014). Of course, the normalization of racism, misogyny and

threats against women players and developers remain tolerated if not encouraged by most studios in this $70-billion a year industry (Wingfield, 2014), composed of between 80% to 90% male developers (Todd, 2015). The mental health labels, misogynist and racist language used to undermine Zoe Quinn, Brianna Wu and Anita Sarkeesian—all prominent and vocal women targeted in egregious ways by GG—all suggest the ways that affect is mobilized to render advocates of diversity 'irrational', 'emotionally unstable' 'ideologues' who want to ruin games. The pro-#GG channel Sargon of Akkad recently released several Youtube videos detailing a supposed conspiracy between feminist games academics and journalists colluding to ruin games. In other words, this series of videos (which includes "The Feminist Ideological Conquest of Digital Games Research Association DiGRA" and "How DiGRA caused the end of Gamers") is devoted to attempting to discredit DiGRA's members and academics working to reduce harassment and make games more inclusive, diverse and accessible.

**Conclusion**

Through documenting the "contests for meaning" (Haraway, 1992) over what gets to count as acceptable emotion about gaming and accepted participation in gaming culture we have seen how the events surrounding GG constitute an affective struggle as well as a cultural battle. Although GG began as an interpersonal attack on a feminist developer of the empathy game *Depression Quest* (2013), it became a movement that employs ableist logic by mobilizing the label of Narcissistic Personality Disorder in the struggle over the meaning of games and gamer identity. In other words, GG uses ableist mental health labels to exclude those interested in social justice from the gamer identity while simultaneously resisting feminist and antiracist critiques of videogames. This ejection of feminists from game spaces might be understood as a phenomenon in which it is worse to call somebody a racist than to be a racist (McIntyre, 2006), and is one way we see the contests for affective meaning being waged concerning systemic forms of discrimination. As we have seen, the rhetoric employed by GG uses sexist, racist and ableist assumptions that are embedded in harmful historical state and non-state legacies of oppression. Policing the meaning of video games and the hegemonic gamer identity, GG deploys rhetoric with the aim to both to shore up the borders of what constitutes 'real' games while harassing those invested in broadening these definitions. At the time of writing, many male gamers are boycotting the new multi-player survival game *Rust* due to that fact that the game randomly assigns a gender and race to individual player accounts. While initially "every player appeared in game as a bald white guy"—many players are refusing to play the game due to the change that the lead developer says simply adds "diversity" (Newman, 2016).

In this article, we have intervened in the current feminist discourses surrounding GG. Specifically, we have demonstrated that the growing body of feminist and queer game studies offers tools with which we can address how the racist and misogynistic mythos in the GG movement and in dominant gaming culture is structured through disability rhetoric. Moreover, the ableist language and threats mobilized in pro-GG communities can be understood as an extension of the historical relationship between disability rhetoric and institutional oppression. The growing popularly of empathy games and subsequent backlash against these games speaks volumes about the

ontological claims of mainstream gamers and the policing that is central to maintaining the boundaries of the hegemonic gamer. As we have demonstrated, far from being a new or isolated phenomenon, GG rhetoric is a dramatic, recent example in which those that reject the normative status quo of inequality are discredited. As we have discussed, there is a long historical tradition of stigmatizing those fighting for social justice. From the incarceration of lesbians in psychiatric institutions (1980) to the labelling of slaves with the psychiatric label drapetomania, the use of mental health labels has a long history in state and institutional violence and was used to justify devastating atrocities. We see that the rhetorical techniques of these earlier examples, while appearing in a very different set of power relations, is being employed by actors in online forums, bulletin boards, social media spaces and now alt-right news to encourage the suppression of resistance, discredit, and silence feminist critiques of video games and digital culture more broadly. Building on the intersectional feminist lenses currently being applied to video games offers a productive set of tools for developing disability game studies. The production of a rigorous disability games studies framework may provide a way to examine how games could become more inclusive and positive spaces for emotional expression and the building of compassion. Perhaps by embracing and re-appropriating the pejorative label Social Justice Warrior we can begin envisioning more inclusive gaming communities.

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# The Disregarded HIV Prevention Strategies—Their Potential to Uphold the Pandemic, and the Challenges Facing Societies

**Reinhard H. Dennin**

**Abstract**

*The ongoing spread of HIV after sobering news about the goal "End of AIDS" is not encouraging, apart from regional differences. We focus on the consequences of the two essentially failed HIV prevention strategies in certain countries. The first failed because the correct messages concerning preventive behavior did not reach the required levels of target populations to interrupt HIV infection chains. There was a lack of appropriate framework conditions for the target populations to engage in the required scale. The additional biomedical strategy "Treatment as Prevention" didn't achieve the breakthrough as was hoped. The consequences thereof affect the financial burden on societies, which can take several decades. We draw attention to the unbalanced principles of proportionality to which governments are committed, but which are practiced in favor of those vulnerable people; these people abuse their autonomy and contribute to the further spread of HIV at the expense of financial burdens, social and medical care systems; this behavior is tolerated, although the transmission of HIV is mostly preventable. We point to extreme tendencies, such as the chem-sex settings, whose unswayableparticipants engage in indirect violence against the societies. Another possible consequence of the still uncontrolled spread of HIV is the potential for HIV to increase its virulence.*

**Keywords:** HIV Prevention, HIV Exceptionalism, Indirect Violence, Lack of Control, Lack of Compliance

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## 1. Introduction

Many governments around the globe have adopted guidelines for the prevention and containment of the HIV-1 (HIV) pandemic given by the new public health (NPH) based strategy. Despite this current prevention strategy in its numerous variants including regional health care programs, the dynamic of the HIV pandemic continues with about 1.8 million newly infected people globally in 2017 [1] . The HIV pandemic is perceived as a global challenge and threat to public health. In addition, the treatment as prevention (TASP) concept was promoted in the early 2000s; it is part of the UNAIDS 90-90-90 project. Because no restrictions were imposed, these strategies have indirectly brought motivation to many of the "at-risk" people1 to maintain risky behaviors that continue the spread of HIV. From the beginning, these vulnerable people were protected by a taboo in spite of their non-cooperation with the NPH strategy. We focus on the HIV based pandemic. The local HIV-2 epidemics are mainly confined to West African countries.

The prospects must not remain fixed solely on the epidemiological development of the HIV epidemic, but must also take into account the social and financial consequences. At-risk people cause immeasurable harm to the societies already burdened with the significant costs caused by their contra-prevention behaviors. The financial burdens may last one to two generations at least, even in the case, the UNAIDS project should work.

We intend to point out what kind of challenges have to be expected and which frameworks are required by state constitutions if the spread of HIV cannot be restricted under UNAIDS guidelines.

The methodological approach: 1) By screening the relevant Journals that focus on HIV/AIDS, STIs; 2) By screening medical information services that cover a broad spectrum of scientific journals regarding, example given, co-infections of different kind, co-morbidities that develop due to the insufficient immune-system caused by HIV, use of recreational drugs like crystal meth and more; 3) By using certain keywords in differing combinations which cover the issues we intended to discuss in our article.

## 2. Epidemiologic

Facts for the European Union/European Economic Area (EU/EEA) and the WHO European Region: The cumulative number of new HIV diagnoses in the EU/EEA and other countries of the WHO European Region reveal a continuing increase in new HIV diagnoses.

Although there are indications to reach the UNAIDS 90-90-90 HIV target in certain countries of the WHO European Region [2] , the actual epidemiology in the European Region is not calming: "The HIV epidemic continues to rise at an alarming pace in the European Region, mostly in its eastern part, which is home to almost 80% of the 160,000 new HIV diagnoses."2 "Sexual transmission between men was the most common mode in the EU/EEA and transmission through heterosexual contact and injecting drug use was the main reported transmission modes in the east of the region." [3] . For HIV in China see [4] , in Germany [5] , in Russia concerning the presently most highly at-risk group, the injecting drug users (IDU) [6] .

## 3. HIV Prevention Strategies and Concepts

Guidelines for the prevention and alleviation of the HIV pandemic/epidemics are given by the commonly applied New Public Health based strategy, also called public learning. Its guiding purpose includes using correct messages in trying to influence at-risk people [7] at the cognitive level towards safe sex and safe use behavior to lower the density of HIV infected people in their communities. These messages are distributed both by mass communication for the general public and individuals; in particular, they should influence individual sexual behavior. However, it is reasonably useful only for people who are both able, e. g., by education, as well as the willingness to understand and to follow the messages correctly3. The designers of these concepts have preconditioned that the vast majority of the people addressed can understand and can comply with the messages. However, they have ignored both the complexness of the emotional levels of the vulnerable people as well as people in severe psychological situations, people already suffering from drug use and many others who are not able, for different reasons, to understand the messages. Proponents of these concepts have expected that even the vulnerable people would also respond appropriately by renouncing any risky behavior. They hoped to be able to interrupt the previously self-sustaining HIV infection chains. The assumption that behavioral control of these individuals with extremely instinctual predispositions could be reached with the right messages permanently and time-stably was a significant miscalculation.

At what occasions do HIV infections happen? First, it depends on different ingrained social, culturalor local traditions for sexual behavior and drug use in different parts of the globe. And, often overlooked the “sex industry” [8] . We focus on the Western World, in particular, Germany, the European Union, and Asia, in particular, China, but show interconnecting international topics. Second, HIV transmission situations range from spontaneous, casual encounters/ventures, small groups joining at bare-backing events and chemsex settings—often professionally organized via local or “geosocial” dating apps. Third, HIV infection most commonly occurs via human-to-human transmission by sex transfer in its various variants or through the exchange of HIV-contaminated items among injected drug users. A study on “Syringe Service Programs in the United States” revealed the problems with services to help these people [9] . Also, mother to child transmission (MTC) happens, in particular in low-income countries; HIV-infection by MTC or blood transfusion is very rare in high-income countries.

The designers of prevention strategies in their various variables have not considered or have neglected the systemic multiplication potential in the wake of high promiscuity within the men sex with men (MSM) communities and settings of IDUs. These people can both infect several partners with HIV and other STIs or acquire them in a short time.

There is a reason to reconsider the “bottleneck” concept of HIV infection [10] concerning the “multiplicity infection by HIV-1 in MSM” [11] . These findings may be seen as favoring conditions for the evolution of HIV.

The epidemiological development of the HIV epidemic in Eastern Europe and Central Asia [12] , Western Europe and other countries with liberal based constitutions proves that too many of these vulnerable people continue to abuse the principle of freedom of the legal systems that include “the obligation to avoid any harm to other

people." The fact is that these NPH-based strategies have ignored the libidinous, high-risk sexual behaviors, in particular, of the at-risk people; instead, these strategies are still based on liberal concepts, i.e., sexual self-determination without any restrictions. In the past decades, the threatening effects there of have been reflected in the increasing prevalence of HIV-infected patients [13] . Therefore, the HIV prevention strategies have failed to convince these vulnerable people to pursue risk-free behavior guided by self-discipline and social responsibility.

## 4. HIV Exceptionalism [14]

### 4.1. The First Stage of Consequences

With the interconnection of no-name-reporting of an HIV-positive test, in contrast to hepatitis B (HVB) and hepatitis C (HCV) in certain countries, anonymity was guaranteed, no back-tracing was implemented to find index patients in order to provide them counseling and offer medical help, no mandatory duty to disclose his/her HIV-positive status to their partner(s), in particular concerning the developed, high-income countries. Name reporting of, e.g., STIs are made for the collective protection of health. The reluctance against testing for HIV is based on a broad diversity of arguments from incomplete engagement [15] to a definite rejection of testing offers. Various tailor-made testing strategies could help to reach the target persons [16] [17] , and to link people testing positive for HIV to health care settings.

The consequences of the effectively failed current prevention strategies can be demonstrated by information from the European Center for Disease Control and Prevention (ECDC) on late presenters: one out of two people tested positive for HIV is diagnosed late [18] . A study in 13 European cities revealed about one third of MSM were undiagnosed [19] . Furthermore, based on an ECDC study: "nearly one in six new HIV diagnoses in Europe are among people over 50" with late diagnosis at 3%" [20] .

Regarding the situation of the "late presenters" in China, only data for certain regions are available [21] .

In the US, the same trend was shown for older people [22] . Late diagnosis of HIV corresponds with a relatively high concentration of HIV (HIV VL) in the blood and correlates to the high infectiousness of these people. The CD4+ T helper cell count in the blood is an indicator of the immune status; CD4+counts above 500 per 1 microliter specifya "normal" range in healthy individuals. However, in patients infected with HIV, this virus infects and destroys the CD4+ cells; their number, therefore, decreases with time. Treatment with antiretroviral drugs according to the TASP5 concept can stop and reverse this process. The report provided by the ECDC for EU/EEA presents the rate of "Late diagnosis" for 2016 (Figure 1) regarding the scaledCD4+ counts.

The consequences: This complex situation of no-name reporting and the late presenters favors the maintenance of HIV circulation in the human populations and benefits the intricate traits of the HIV to evolve continuously. There is marked variability in the rate of HIV disease progression, depending on genetic factors of infected people as well as HIV replication. After infection of a person, besides the infection of the CD4+ T helper cells, HIV crosses the blood-brain barrier early and infiltrates the central nervous system (CNS) [23] [24] . Late complications may occur: neurocognitive deficits in different stages and behavior disorders [25] [26] [27] . Different populations of these late presenters who are unaware of their HIV infection

for several years may become exceedingly unable to understand the correct messages of the prevention campaigns and cannot follow them; this entails that they can both infect many people for several years or acquire a super infection depending on their sexual lifestyle. They represent an ongoing hidden source that contributes to maintaining the spread of HIV. This situation is due to liberal concepts without any kind of control.

The TASP concept was promoted in 2008; it is part of the UNAIDS 90-90-90 project6. The slogan "Test and Treat" [28] is correct and sounds helpfully, but in order to be successful the TASP/UNAIDS concepts require both 1) testing as early as possible and 2) stringent cooperation/adherence from those taking anti-HIV (ART)7 medications and the obeying of the prevention messages. The sooner the HIV diagnosis is made, the sooner the medication with ART can be initiated, thus helping to hold the HIV reservoirs down and significantly improving the immune status. Late presenters, already partly suffering from restricted cognitive abilities, might have reduced ability to adhere when receiving ART. Furthermore, reports on unnoticed occurrences of blips [29] , HIV RNA rebound [30] and low level viremia [31] in people with ongoing ART medications should raise awareness towards infectiousness regarding the TASP/UNAIDS concepts.

Certain countries (e.g., low-income countries with a high prevalence of HIV and high-income ones with a low prevalence of HIV) report to reach the goals set by the UNAIDS [32] . However, in other countries there are entirely different prospects, local epidemics could get out of control. Such a development was already foreseen in 2004 "HIV outpaces global response [33] .

Meanwhile, it is known that depending on the country, too many HIV-naïve people and those under the ART developed reduced risk perception, followed by complacency, frivolity, etc., oftener resulting in "safer sex fatigue" [34] [35] [36] . They have accepted treatment optimism with risk-taking [37] , so as to continue jauntily with sexually risky lifestyles. Three studies performed in Sub-Sahara [38] , South Africa [39] and the Netherlands [40] revealed in an exemplary way the complexity of risk perception. Too many bearers of at-risk behavior in the context of this article disregard, for various reasons, a basic rule of our societies: "avoid any harm to other people" [41] . The safer-sex-fatigues have to be extended to HCV: In the context of the very effective treatment options available for HCV, both increasing rates of first and reinfection with HCV are reported [42] . Failing HCV antiviral treatment in the context of reinfection with different HCV genotypes should raise awareness [43] .

Regarding ART resistant HIV, quite different situations have been reported: no serious situation in the US [44] and certain areas of China [45] , situations concerning "pretreatment resistance" in low and middle-income countries [46] [47] and warnings regarding the UNAIDS project [48] .

4.2. The Second Stage of Consequences

In contrast to old public health (OPH) regimentations, HIV was not ranked as a regular infection like hepatitis B and hepatitis C in Germany. OPH bases on name reporting and back tracing to find index patients to help them at different levels and for the collective health protection.

For HIV infection, the NPH includes a government-granted taboo without any injunctions or legal prerequisites like a liability risk. This policy has also led to at-risk people from the various categories, in particular, the MSM in the EU8, having established rules for them to continue and to develop situations guided by risky behavior undisturbed; these rules are directed against the interests of societies. Policy makers tolerate the mentality of too many at-risk people being allowed to live without social responsibility to the detriment of the common good, unless, inter alia, a preventive anti-HIV vaccine is developed [49] . This taboo is supported by PrEP (pre-exposure prophylaxis with ART) [50] , ART as part of the TASP concept and the resulting expectation of an increased life expectancy [51] . The potentiation of bodily harm caused by adding the use of recreational drugs is included. The PrEP itself has "… the potential to reduce new HIV infections" [52] , but if abused, e.g., with persistent high-risk practices such as unprotected sex (e.g., anal intercourse), such situations are known to facilitate both the transmission and acquisition of other sexually transmitted infections (STIs) [53] . These situations provide additional proof of the insufficient prevention strategies/concepts and provide harmful aspects for the future spread of HIV. Too many of theat-risk people have taken lifesaving medications without a quid pro quo; this public care was and still is not appreciated.

Overlapping epidemics developed by vulnerable people: "at-risk" populations such as IDU and in the context of high promiscuity, e.g., by MSM and heterosexual "geosocial" networking apps, female sex workers, etc., depending on the ethnicity, country and certain aspects regarding prison inmates [54] . Meanwhile, the definition of "at-risk" has to be extended to heterosexual communities too. And there are developments, expected ones, and additional new trends that could be hazardous for the goal set to end the HIV pandemic in general and affected countries in particular. Bare backing, "… refers to intentional unsafe anal sex" [55] and chemsex settings [56] [57] .

1) To be related to most professionally organized chemsex parties, i.e., sexualized drug use: sex and co-consuming psychoactive drugs, also named recreational drugs [58] [59] [60] . Such kinds of drugs like methamphetamine (crystal meth) are welcomed to "… initiate, enhance, and prolong sexual encounters"9 [61] and to reduce inhibitions and pains when having extreme "high-risk" sex including "sexual assault" [62] .

2) These settings can represent highly concentrated densities of people infected with HIV and other STI, like syphilis, HCV [63] and HPV (high-risk types like HPV 16) [64] . These settings provide uncontrolled platforms for the spread of HIV and other STIs, which in turn are further indicators of failed prevention strategies. Also, mono- or coinfections with STI(s) are in contrast to the specifications of the TASP concept (see footnote v).

3) These settings with or without drug use that enable a higher density of HIV-infected people are also known as "HIV transmission clusters" [65] [66] . Overlapping partnerships can be established in the context of high promiscuity, e.g., promoted by both MSM and heterosexual "geosocial" networking apps [67] [68] [69] . Such kinds of settings provide effective platforms for HIV for blending its different clades (details see

below, c.). The enormous potential of the dynamics of the evolution of HIV is also present in the P.R. China [70] [71] [72] [73] .

4.3. The Third Stage of Consequences

Based on the exceptional status of HIV, these situations have emerged in favor of the uncontrollable people of the risk groups. They arose from a taboo that protects this minority of people against any legal consequences. This liberal approach is currently maintained, although the personal transfer of HIV is considered as bodily injury or as a homicidal offense and is classified as a criminal offense in Germany.

The evolution of HIV bases on two foundations: first, it's an intrinsic characteristic of the HIV RNA genome to mutate rapidly. The generated mutations have the potential to escape both the external attacks from ART ("ART resistance") and the immune system of its host; the "viral escape mutations" due to CD8+ T cell responses might have hazardous potential [74] . Second, a preexisting HIV infection does not detain a superinfection; settings such as bareback and chemsex, in particular, have been classified as clusters for blending HIV from different clades, resulting in circulating recombinant forms (CRF) [75] [76] . The behavior of too many of the highest risk-taking people who are HIV-naïve and those already infected assists the ongoing evolution of HIV [77] . This is because these people reject to follow the correct messages of the prevention campaigns; otherwise, HIV would not stand a chance.

Without ART, most of the HIV infected people would die within several years after infection; but with ART these people can expect a normal life expectancy, but not all of them. In spite of ART, HIV persists in certain CD4+T cells [78] [79] and remains replication-competent [80] . Concepts like "Kick and Kill" to eliminate these reservoirs of HIV does not work yet [81] .

## 5. Prospects

This prevention strategy has allowed both undiagnosed HIV-infected people as well as already those already diagnosed as HIV-positive to remain hidden from any surveillance in most countries. The TASP concept has enabled vulnerable people to refrain from preventive behavior according to the prevention reports. The TASP concept is taken as a guarantee that they no longer had to fear the HIV infection, and too many of them continue transmitting HIV—and the overlooked gaps, e.g., insufficient suppression of HIV VL and its consequences.

Indirectly, governments that follow the NPH strategy, with its various variants without any legal framework to limit the misconduct of vulnerable people, have created conditions that in spite of TASP may help to sustain the HIV epidemic, at least at a reduced level. By scientific terms, this means that societies, health care systems and international funds help most of those taking ART to achieve a near-regular life expectancy, but indirectly, they also help many of them with insufficiently suppressed HIV VL to maintain the spread of HIV in many countries [82] . It is like a vicious circle.

What these people, the at-risk people, per se, and those of the heterosexual sceneries, are mostly intentionally doing when spreading HIV reflects an infringement against the correct messages of the prevention campaigns and is directed against the societies.

Governments who follow this kind of a liberal approach tolerate the selfish behavior of these vulnerable people, who take this generosity of an unlimited

autonomy as a legally protected interest. Governments have allowed these unswayable people to continue their misdemeanor when spreading HIV and other STIs; these trends have reached a massive scale also in developed countries.

This situation corresponds to a certain kind of violence of those people against the current law not to harm other people and against the states, the governments and the societies that are in duty to help them when needed.

The governments are giving way; they tolerate this violence against societies as a whole.

Specific questions must gain momentum such as: How should the principle of proportionality be weighed? Two objectives need to be addressed: 1) Personal rights: Is there a limit to the current taboo on the indefensible people who sustain the spread of HIV? 2) The financial burden and its limitations: Recent publications show that funding, e.g., for ART, medical and social care, for HIV-infected individuals is limited. Given that our societies are reaching their limits: Is unlimited tolerance still valid for people who sustain the spread of HIV? Warnings regarding "A growing global issue" are long known [83] . The current status contrasts the governments' duties to protect the societies from awkward, unpredictable, challenging impacts on the common good. As for selfish behavior, how long can the consequences of the misuse of granted freedoms be imposed on societies and when are restrictions imposed [84] ? Many Governments seem to have ignored this Principle of Proportionality because they also need to protect Public Health Issues—not just the interests of people who continue to spread HIV.

Some countries have noticed this problem. While protecting the legal rights of these vulnerable groups, and since these people are also high-risk groups, for public health, they have also been intervened and regulated. For example, in China, the relevant government departments are aware of the necessity of combining legal control with behavioral intervention. At the same time, appropriate measures of coordination and division were initially designed. Such as specific interventions have been made for the behavior of drug addicts, sex workers and MSM [85] .

In addition to the basic legal responsibility of the government for AIDS prevention and control, community forces and non-governmental organizations also should be encouraged to participate in AIDS prevention and control projects. The community can provide life support, psychological counseling, and behavior correction for AIDS patients. The government should increase the input of service personnel, financial resources and material resources in community service and institutionalize community support. Non-governmental organizations have advantages in AIDS prevention and control because of their flexibility, effectiveness and public welfare, which can contact the group that the government hardly gets close to. Moreover, some members of non-government organizations are made up of AIDS patients or their relatives, and the experience of them is more convincing to other AIDS patients. Non-governmental organizations play a role with the government and the community to build a more perfect and efficient AIDS prevention and control system and mechanism.

In the context of the not sufficiently curbed spread of HIV, entirely different consequences have to be addressed too: The potential of an increasing virulence of the HIV. The goal of UNAIDS that the third 90% of treated people with suppressed HIV (i.e.,

10% are not suppressed) will contribute to the END of AIDS might not meet the realities. In the complex context of, for example, the late presenters, the geosocial sexual networks, the vulnerable people who do not follow prevention campaigns, all of these influences could lead to the ongoing spread of HIV. The more people spread HIV, the more effective it is for HIV to promote its virulence [86] [87] . An extreme situation has gained thanks to no framing restrictions for these people.

**6. Comorbidities**

HIV and coinfection with other STI like HCV, especially concerning coinfections of the CNS, have the potential to induce a broad spectrum of neurocognitive deficits [88] [89] . Regarding the increasing HCV mono-infections among the at-risk populations, the extra-hepatic manifestations include the CNS too [90] . HPV infections are also known to follow sexual transmission routes, causing cervical, anal as well as oropharyngeal cancers [91] [92] . Those vulnerable people who engage in chemsex settings are at risk for connected disorders, e.g., by crystal meth [93] . Co-consumption of psychoactive drugs has both short- term restrictions of cognitive self-control, disinhibition, as well as long-term consequences such as psychotic symptoms in the case of cannabis [94] , drug addiction and the health consequences of addiction, including unemployment status. In the context of consuming psychoactive drugs when having sex, the long-term effects on the health of these consumers must be considered apart from short-term consequences like an inebriation just for days. The use of cannabis has to be seen in the context of cardiovascular diseases (CVD) [95] . This situation also applies to their behavior in the context of limited ability to follow the messages for preventive behavior: cognitive deficits or disorders of various degrees. Cardiovascular risks [96] and heart failure, possibly evoking from protease inhibitors (PI) [97] , in people living with HIV pose particular challenges.

7. Legal Aspects

The prevention and treatment of AIDS is not only a medical issue but also a social issue. It requires a multidisciplinary study of ethics, sociology, economics, and law. The idea of combining AIDS prevention and human rights protection has become a basic consensus in the international community through long-term practice. Experience in AIDS prevention and human rights protection in countries around the world shows that there is no contradiction between AIDS control and human rights protection. Prevention, treatment, care, and support are interrelated and mutually reinforcing. Past work has neglected the intrinsic link between them, leading to many problems, such as insufficient protection of family members of the patients and ignoring community rights, resulting in significantly reduced anti-epidemic effects. Relevant intellectual property laws, customs laws, and tax laws have hindered the supply of cheap and effective drugs and medical devices; unscientific media and even discriminatory propaganda have led to social panic and intensified social conflicts.

Order and the realization of justice cannot be separated from the law, but at present, it seems that formal legal norms enacted by the state or international organizations are not sufficient to accomplish this task. The misunderstanding of legislators and policymakers leads to the fact that many effective preventive measures, in theory, cannot play their due role in reality.

"The International Guidelines on AIDS and Human Rights" [98] and "The Basic Declaration on the Human Rights of AIDS Patients" [99] places the protection of the social rights of AIDS patients first. They are paying more attention to protecting the rights of personality, equality and freedom of AIDS patients. "The International Guidelines on AIDS and Human Rights" include support for community partnerships, legal aid services, a supportive environment, and changes in discriminatory attitudes through education, training and the media. "The basic Declaration on the human rights of AIDS patients" also lists the right to seek and enjoy relief, the right to education, the right to enjoy a certain standard of living and social security as the fundamental rights of AIDS patients. While if there is an abuse of freedom principle for AIDS patients, the legal concepts and principles will ignore the right to know of healthy people and threaten the right to their health [100] .

In addition, relevant guidelines issued by international organizations such as "The International Guidelines on AIDS and Human Rights", also have limitations, including the principles of sex work, MSM, the status of women, drug use, voluntary testing and the emphasis on individual human rights protection, which are relevant to the specific national conditions of many countries. Although to solve this problem, the guidelines have also made some efforts in the formulation, such as emphasizing the obligations of countries to implement international human rights standards and requiring countries to implement AIDS-related programs pragmatically in specific national circumstances and to protect public health and human rights. However," the International Guidelines on AIDS and Human Rights" overemphasizes international human rights standards and overly neglects the particularity of human rights, which cannot be entirely remedied by relying solely on specific measures. For example, in China, the right of privacy for AIDS is special. The general lack of AIDS-related knowledge among ordinary citizens in Chinese society makes AIDS considered an infectious disease related to moral fouling. HIV testing can cause AIDS patients to fear that their privacy will be discriminated after being leaked, so it is difficult to achieve voluntary testing through legislation.

Can help be expected from the law? Apart from very rare cases that came to court (in Germany), thus far: the legal systems are powerless. The law has lost its normative power in the context of the issues discussed here [101] [102] . This powerlessness of legal systems of certain countries in Europe and Central Asia is presented in the "ECDC Evidence Brief: HIV and laws and policies in Europe" [103] .

In Germany, no person gets punished for being HIV-infected. That would be a clear constitutional violation. This is even though unprotected sexual contact between an infected person and a non-infected partner is the starting point for criminal consideration.

However, penalizing the infected person who has infected another person is the exception, as the courts must be able to prove a causal relationship between (sexual) contact and infection of the partner. This situation leads to the legal problem that the personal causality of a new HIV infection is barely detectable years after infection. The HIV infection is usually fatal. ART does not take the blemish of legal relevance to HIV infection.

The criminal treatment of HIV transmission is strictly legal. If a person intentionally or negligently kills or injures another person, it is immaterial how it happened. But before the law and before the criminal law, all human beings are equal, and it is, of course, the ethical principle not to harm a person. In Germany, a person becomes not punished for being HIV-positive. This person will only be penalized if it intentionally or negligently killed or injured another person, which can also happen through the transmission of HIV.

The evaluations show that the forgoing governments prefer to recede from the violence of vulnerable people who remain resistant to current prevention campaigns. The governments admit that these people can follow their sexual selfishness next to drug abuse unchecked, to the detriment of the societies.

**8. The Costs**

As a consequence of liberal prevention strategies without any legal measures or other regulation for people who continue spreading HIV, the inevitable results are: Governments pursuing these inadequate policies forcing the health care systems and the societies to incur the necessary costs for at least one or two generations [104] [105] 10. A multitude of prevention programs adapted to the various behaviors have to be developed to convince the most vulnerable people to join testing and medical care offers. The German Ministry of Health (BMG) stated already in 2016 to have kept the HIV epidemic at a low level [106] . Costs of the HIV epidemic have been published for the UK [107] and USA [108] . Regarding Europe, there are already warnings that "Currently, two out of three EU/EEA countries tell us that they do not have sufficient funding for prevention interventions…" [109] . More general [110] and sobering reports on stalled funds from different sources have been reported [111] . In China, the main source of funds is the central financial allocation, as well as local financial allocation, international organizations and foreign government funds. China's "AIDS Prevention and Control Regulations" is based on the principle of prevention and combination of prevention and control. A considerable proportion is used for AIDS propaganda of medical knowledge and legal policy of AIDS.

**9. Conclusions**

While considerable progress has been achieved with ART/HAART, nonetheless, too many people of the diverse at-risk categories unprecedentedly continue the spread of HIV. Support by "Adherence to the care…" [112] [113] and online services [114] may be helpful to some degree. The proposals published by the ECDC/WHO are not innovative: "Multi-component interventions and the consideration of new strategies, such as the inclusion of pre-exposure prophylaxis for HIV, self-testing and assisted partner notification into the package of prevention and control interventions, could help to curb this increasing trend [115] ." These intentions don't match the realities of too many unswayable people and those with low educational levels, marginalized, homeless people unless "control interventions" can be enforced. If the current HIV prevention concepts are to be modified, then differentiated insights into the behaviors of at-risk persons must be taken into account [116] . Sex in the context of social responsibility has to be addressed [117] . The social contract states: everybody has duties to the community, sexual freedom and individual liberty must be limited to enforce these "duties". This condition is following the Article 29 of the Human Rights

Declaration. Cooperation with the prevention campaigns is required. A multitude of facts reveals that the global community is reaching a crossroad. Individual governments are facing crucial decisions. It is important to strengthen cooperation between governments, communities, non-profit organizations and people affected by AIDS, and to focus on interdisciplinary AIDS research results.

Given the current status of the ongoing spread of HIV in many regions of the globe, the validity of current policies has to be challenged. If it is not possible to persuade the incorrigible at-risk people of various categories to cooperate with the guidelines of prevention messages, then a humanitarian catastrophe may develop.

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# An Online Library of Science-Based HIV Prevention Resources

**Josefina J. Card**

**Abstract**

*This paper introduces the online Sociometrics Social, Behavioral, and Health Sciences Library, an exciting new science-based resource for HIV/AIDS researchers, health educators, and clinicians. The over 400 products in the Sociometrics Library supplement the online publications—journal articles, books, reports, monographs—that have been the focus of scientific research libraries and publishers to date, both printed and online. Examples of the innovative science-based products that serve as the library's content include: Evidence-based interventions and programs (EBIs/EBPs) that evaluation research has shown to be effective in preventing HIV or its risky social and behavioral antecedents; primary research data and survey instruments; and interactive, multimedia training tools and courses to build HIV professionals' capacity to implement EBPs with fidelity and to cooperate with evaluators in the assessment of their effectiveness. A Scientist Expert Panel has guided and will continue to guide product selection and acquisition, ensuring the collection's continuing technical merit, research utility, and relevance for practice and policy. The Sociometrics Library aims to become the dominant online source of behavioral and social science-based HIV research by-products, operationally sustainable and able to stay up-to-date both from a technological and scientific perspective.*

**Keywords:** *HIV, AIDS, STI, Data, Instruments, Effective Programs, Evidence-Based Programs, Capacity Building Tools, Researchers, HIV Educators, HIV Practitioners*

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## 1. Introduction

Despite global efforts to address the AIDS epidemic, HIV infection remains a significant problem, particularly for low-resource countries and US minority populations who are disproportionately carrying the HIV burden [1] [2] [3] . AIDS and related illnesses are the leading cause of death among women ages 15 to 49 globally, and the second leading cause of death for young women ages 15 to 24 in Africa [4] . While AIDS-related deaths have declined in some regions of the world, including eastern and southern Africa and North America, AIDS-related mortality has increased over the past decade in the Middle East and North Africa by 48%, and in Eastern Europe and Central Asia by 38% [4] .

The populations most profoundly affected by the HIV epidemic include specific racial and ethnic minority groups, gay or bisexual men who have sex with other men (MSM), sex workers, and injection drug users. In countries across the world, HIV prevalence among key subpopulations is often substantially higher than among the general population [4] . In the United States, MSM accounted for 67% of new HIV infections and 83% of new infections in males in 2016 [5] . Among racial and ethnic groups in the US, African American and Hispanic men and women continue to be at higher risk of contracting HIV and yet have lower access to testing, prevention, and healthcare [2] [3] [6] . According to the CDC, the US Centers for Disease Control and Prevention, African Americans and Hispanics represent 30% of the US population but accounted for 69% of new HIV infections in 2016 [5] .

Evidence-Based Resources for Reducing HIV Transmission

As a result, numerous programs and strategies have been developed across the globe to reduce HIV transmission and improve related outcomes [7] [8] [9] [10] [11] . Many such programs have been proven effective in changing behaviors, such as risky sexual or injection drug-related behaviors, that increase the probability of HIV transmission [12] - [17] . These effective programs are called evidence-based interventions (EBIs) or evidence-based programs (EBPs). Typically, EBPs not only inform participants with relevant knowledge and facts, but also teach new skills and give participants the opportunity to practice the skills with techniques like modeling, role-playing, and games.

Considerable research has demonstrated that select EBPs can decrease risky sexual and drug-use behaviors among populations heavily impacted by HIV/AIDS, including men who have sex with men [18] [19] [20] ; injection drug users [21] [22] ; young people [23] ; and other high-risk populations. This is true in both high- and low-resource countries [24] [25] [26] [27] and across age groups such as youth and adults [28] [29] [30] . The success of EBPs in reducing HIV transmission among diverse populations, including high risk groups, has led organizations such as the CDC, NIH (the US National Institutes of Health), and WHO (the World Health Organization) to actively promote the use of EBPs [31] [32] [33] [34] .

Many factors, however, continue to obstruct EBPs' wide dissemination and sustained implementation [33] [35] [36] [37] [38] . The most prominent barriers to EBP uptake and implementation are the lack of low-cost access to EBPs; the high cost and lack of availability of technical assistance; insufficient organizational capacity among community-based organizations implementing the EBPs; inadequate buy-in

among staff; a lack of EBP fit with the personnel, money and time constraints of the organization; and limited knowledge about adaptation of EBPs to the local context [35] [38] [39] . Public health practitioners frequently report that they are stretched too thin. They are often expected to remain up-to-date on literature, seek out effective programs, perform program adaptations for their specific target audiences, and find other practitioners to share lessons learned from the field or exchange advice. Each step of the process requires a considerable time commitment from already busy health educators and providers, creating significant challenges.

Program adaptation to the local context can be a particularly weighty barrier, given the difficulty in determining how to adapt a program for new contexts while preserving the core components underlying the program's efficacy. However, program adaptation is itself an essential practice, as research has shown that programs must be tailored to appropriately address the cultural backgrounds, developmental levels, and community contexts of the target population [40] [41] . While adaptations are vital to an EBP's on going success, inappropriate modification of program components often reduces a program's efficacy and prevents it from changing behavior. Studies have shown that organizations frequently modify core program content [42] [43] [44] . Practitioners lack helpful, easily understood, science-based tools to help them apply the concepts of fidelity and flexibility to their work [45] [46] . Modifications are often made to adapt, alter or delete program content, scope, and/or delivery method to accommodate real-world circumstances such as time constraints, varying population or setting needs, or unavailability of organizational resources. Many such modifications are done without guidance for how the changes affect fidelity, core elements and desired outcomes [47] [48] .

New tools and resources are required to bridge the gap between research and practice. There is a need not only for widespread identification and dissemination of EBPs, but also for tools and resources that support program fidelity, appropriate adaptation of EBPs to specific contexts, and program engagement.

Program evaluation is also of significance. Evaluation enables practitioners to understand why and in what areas their implementation of an EBP has succeeded or failed, the impact of each program component, and how to improve future implementations [49] . However, health practitioners often experience difficulty in evaluating their interventions because of factors such as a lack of research knowledge and training; difficulty developing questionnaires and other evaluation tools; lack of staff time to conduct evaluations; and low funding coupled with high evaluation costs [50] [51] .

To address these challenges, Sociometrics Corporation has developed an online suite of research-based products and resources: the Sociometrics Social, Behavioral, and Health Sciences Library (https://www.socio.com/). This online library aims to address these challenges by expanding and updating the search for effective HIV prevention EBPs and HIV-related datasets; identifying EBPs that meet established effectiveness criteria; promoting easy dissemination and uptake of these EBPs across implementation settings, including low-resource regions; providing capacity-building tools that support program adaptation and fidelity; and enabling widespread evaluation of program efficacy by simplifying data collection, analysis, and sharing.

## 2. Methods

### 2.1. Collection of Resources

For over three decades, with funding from the NIH and CDC, Sociometrics has developed multiple topically-focused collections of evidence-based programs (EBPs), datasets, and capacity-building tools for health and public health professionals. Two of these collections—the HIV/AIDS Prevention Program Archive (HAPPA) and the Global HIV Archive (GHA)—contain EBPs that have been proven effective in reducing the sexual and drug-related behaviors that put one at risk of HIV/AIDS/STI transmission. The companion HIV/AIDS/STI Data Archive includes studies that provide descriptive and comparative data on the behavioral and social antecedents and consequences of HIV, AIDS, and sexually transmitted infections (STIs). Sociometrics has also developed capacity-building tools to aid in implementing, adapting, and evaluating EBPs.

#### 2.1.1. EBP and Data Collections

Sociometrics' collections of EBPs and datasets were developed using a systematic process of identification (by Sociometrics staff), review and selection (by Scientist Expert Panels), acquisition (from the developer of the EBP or dataset) and processing for public use (by Sociometrics staff). A Scientist Expert Panel of four to six members was established for each topically-focused collection; panelists were researchers considered experts in the topic area. The Scientist Expert Panels developed resource selection criteria in conjunction with Sociometrics' staff of scientists. For EBPs, these criteria included the program's technical merit, replicability, and positive outcomes; the criteria for datasets included technical quality, substantive utility, relevance, and disciplinary balance. Candidate programs and datasets were then identified using extensive searches of relevant scientific literature, and briefing materials were prepared for each candidate resource. These briefing materials were provided to the Scientist Expert Panels, who assigned each resource a priority score for inclusion in Sociometrics' Library. Sociometrics contacted the developer(s), author(s), and/or investigator(s) of the selected programs or datasets to obtain permission to include the resource in the Sociometrics Library and to disseminate it for public use. Finally, obtained resources were packaged in a user-friendly way to facilitate replication in a new setting. For EBPs, packaging included a user's guide containing the curriculum and describing the evidence for its effectiveness; as well as all facilitator, participant, and evaluation materials needed to faithfully replicate and evaluate the program in a new setting. For datasets, the packaging included a user's guide describing the dataset's sample, data collection methods, and included variables. The raw data and analytic SAS and SPSS program statements were included, as were documentation files such as instruments, codebooks, and frequencies.

#### 2.1.2. Capacity-Building Tools

To support the exemplary EBP and data collections, Sociometrics' scientists developed capacity-building tools and resources for ongoing education of HIV professionals. These tools aim to improve health practitioners' ability to implement EBPs with fidelity and cultural competence, evaluate them, and analyze the resulting data. Resources in the capacity-building collection include training modules focused on how to implement and evaluate specific EBPs; sexual health-related activities and exercises for use in middle and high school classrooms; behavioral skills training tools

for developing and implementing culturally competent programs; and evaluation resource guides and tutorials.

## 3. Results

### 3.1. Library Content

As of this writing, the Sociometrics Social, Behavioral, and Health Sciences Library (https://www.socio.com/) consists of 90 evidence-based programs, 315 datasets, and 22 capacity-building tools for health professionals. HIV/AIDS is a significant focus of the Sociometrics Library: 65 evidence-based programs (Table 1), 29 datasets (Table 2), and 16 capacity-building tools (Table 3) are focused on HIV and HIV prevention. The collection continues to grow. For information on how to submit a science-based HIV dataset, EBP, or capacity-building tool to the Sociometrics Library, please go to https://www.socio.com/submissions.

#### 3.1.1. Evidence-Based HIV Prevention Programs

Table 1 details the HIV-related evidence-based programs (EBPs) in the online Sociometrics Library. A wide variety of programs are included, focused on different countries, target populations, theories of change, and prevention approaches. All of the HIV EBPs have demonstrated a positive impact on reducing sexual and/or injection drug-related behavior(s) that put an individual at risk for transmitting or getting HIV/AIDS. The EBPs are presented in lesson-by-lesson sequence, with all facilitator and participant materials for each session included in view- and/or download-format.

#### 3.1.2. Exemplary Datasets

The Sociometrics Library's datasets address a variety of topics including the incidence and prevalence of specific sexual behaviors; contraceptive and STI-preventive

#### 3.1.3. Capacity-Building Tools for HIV Professionals

The Sociometrics Library offers 16 capacity-building tools aimed at HIV professionals. These resources aim to increase the capacity of HIV educators and prevention providers to adapt, implement, and evaluate HIV prevention programs successfully. Some focus on specific HIV-related EBPs, while others focus on HIV risk reduction more generally. Some are offered in PDF format and others in interactive, multimedia format. Table 3 details the capacity-building resources for HIV professionals available in the Sociometrics Library.

### 3.2. Access

The evidence-based HIV/AIDS EBPs, datasets, and capacity-building tools in Tables 1-3 above can be accessed through individual, group, and institutional subscriptions (contact jjcard@socio.com for access information). Individual subscriptions allow a single health professional or practitioner to access, view, and administer one or more Library resources 24/7 from their computer, tablet, or smartphone. Group subscriptions allow a team of health professionals, researchers, and educators access, view and administration privileges. A group administrator can purchase access for team members and manage access centrally. Finally, an institutional all-access pass can be purchased by community-based organizations, hospitals and health clinics, universities, public health departments, and other interested institutions. This institutional all-access pass grants access to the entire

resource library of 400+ EBPs, datasets, and capacity-building tools in https://www.socio.com/.

## 4. Discussion

The Sociometrics Library is a significant step forward in meeting the research-to-practice needs of frontline HIV prevention practitioners. In order to have a positive impact in the real-world, this library was built on the latest scientific knowledge, duly translated into formats accessible to global workers trying to stem the epidemic. The Sociometrics Library has many innovations, all aimed at facilitating real-world impact:

1) Identification and archiving of HIV prevention programs that science has found to be efficacious in reducing behaviors putting one at risk of HIV transmission. The collection of these validated prevention programs in one place saves health professionals valuable time and costs otherwise spent remaining up-to-date on the prevention literature and seeking out ways to access complete versions of the effective curriculum and implementation materials. The Sociometrics Library of replication-ready resources simplifies a process that currently presents a significant barrier to the use of evidence-based programs by HIV prevention practitioners.

2) Identification and archiving of datasets that science has found to be of high technical merit. The collection of the exemplary HIV/AIDS datasets in one place saves health researchers valuable time and costs otherwise spent remaining up-to-date on the prevention literature and seeking out the best ways to access the data on which publications were based. The Sociometrics Library of analysis-ready raw data and documentation simplifies a process that currently presents a significant barrier to secondary analysis of exemplary data by HIV prevention researchers.

3) Digitization and organization of effective program implementation materials to facilitate global access via the Internet. This innovation allows formerly printed, hard-copy educational products to be accessed at low cost anytime, any place. Health educators can now access prevention programs live during program implementation from their computer, tablet, or mobile phone. The curricula and materials are organized in lesson-by-lesson sequence, enabling easy use of the materials in schools, community-based organizations, clinics and hospitals.

4) Provision of capacity-building tools. The Sociometrics Library also includes science-based capacity-building and professional education tools that directly address some of the most significant challenges that prevention practitioners face when applying science-based research. These tools assist with adaptation of evidence-based programs to local settings, while maintaining the core program elements underlying the program's effectiveness. Other tools describe how to appropriately evaluate prevention efforts and analyze research datasets.

5) Provision of online browsing, search, and filtering capabilities to improve users' ability to find and select relevant products. The Sociometrics Library not only gathers effective programs, datasets, and capacity-building tools in one place, but also enables easy search and navigation within the library itself. Keyword search and filter capabilities by topic, target population, and product type allow users to quickly and easily find the most relevant product(s) for their needs.

6) Provision of original evaluation instruments. In order to encourage re-evaluation of the efficacious programs in a new setting, the Sociometrics Library also

includes the original evaluation instrument used to demonstrate the efficacy of each program. The instrument can be re-used as is, or modified for use in a new evaluation in a new setting. The Sociometrics Library also offers additional, generic resources for program evaluation. The family of evaluation instruments and resources supporting each effective program facilitates re-evaluation in a new setting, to test the robustness of the initial finding of efficaciousness in the original site and to improve future implementations in the local site.

7) Scalable design. The Sociometrics Library was built with both scalable design and a technological infrastructure for ease of future expansion, as other effective programs, datasets, and capacity-building tools are identified. The innovative technological platform allows for the upload and distribution of a wide variety of product and file types, including increasingly common multimedia products.

## 5. Conclusion

The Sociometrics Social, Behavioral, and Health Sciences Library at https://www.socio.com/ is a rich and innovative source of exemplary HIV/AIDS evidence-based programs (EBPs), datasets, and capacity-building tools for the continued professional education of HIV professionals. With several new innovations in prevention programming—such as low cost 24/7 access to all facilitator, student, and evaluation materials comprising a diverse set of effective HIV/AIDS prevention programs; and "responsive design" for use on computers, tablets, and smartphones—the Sociometrics Library facilitates research as well as EBP uptake, implementation, and evaluation across a range of settings, including schools, clinics, community-based organizations, universities, global settings, low-resource settings, and settings with specific minority populations that have shouldered the brunt of the HIV epidemic.

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# Invasive Infections for Endemic Fungi in Pediatrics in Guatemala

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**Abstract**

*Background: Invasive fungal infections are common opportunistic diseases in patients with AIDS, other conditions related to immunodeficiency and healthy infants. Most publications on this subject are related to industrialized countries, and in adult population, with limited data in Latin America (except for Brazil, Colombia, and Argentina), and especially in pediatric population. These patients present a variety of clinical manifestations representing a diagnostic and therapeutic challenge for the health system. Objective: The objective of the study is to describe the epidemiological and laboratory characteristics of children with invasive fungal infections in Guatemala. Methods: A review of the microbiology service database was carried out at Roosevelt Hospital in Guatemala. Positive cultures were taken from children under 15 years of age, in a period of seven years, from 2007 to 2014, with its corresponding medical history. Results: Finally, 23 isolates were documented but only 15 patients were included in the study with complete information; 10* Histoplasma capsulatum *cases, 4* Cryptococcus neoformans *cases and 1* Coccidioidessp *case. The average age was 7 years old for Histoplasma and 9 years old for Criptococo, with an age range from 6 months to 14 years. Around 60% of the patients were older than 5 years, of which, more than two-thirds were HIV positive children without antiretroviral therapy, who presented an invasive fungal infection at the time of HIV diagnosis. These infections are endemic in Guatemala, so the distribution was mostly uniform. Around 80% of the patients had some disease related to immunodeficiency and 70% were infected with human immunodeficiency virus (HIV). The microbiological isolation was from blood, bone marrow, lymph nodes, cerebrospinal fluid and urine. The predominant laboratory findings were decrease in hematological series. The most frequent clinical syndromes were fever, adenomegaly, hepatosplenomegaly, respiratory, gastrointestinal, neurological and weight loss.*

*Mortality rate was 53% (from them, 62% were HIV positive). From these patients, an87% did not receive antifungal treatment in time due to late diagnosis of the*

*infection.*

*Conclusions: These infections should be considered when treating pediatric patients from tropical regions, with nonspecific systemic symptoms and signs, lymph node involvement and hematological alterations related to the mononuclear phagocytic system, mainly if they are patients infected by HIV in an advanced stage, infants, or children with a disease that weakens the immune system. When there is a high suspicion of a fungal infection, screening for HIV is mandatory; cultures should be taken early and together with rapid diagnostic tests. An antifungal treatment should be started immediately and then modified accordingly to laboratory results.*

**Keywords:** Cryptococcosis, Histoplasmosis, Coccidioidomycosis, Invasive Infection, Pediatrics, Immunodeficiency,HIV (Human Immunodeficiency Virus)

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## Introduction

Along the pediatric population, there are some groups with an increased risk for invasive fungal infection (IFI). Within these risk groups, are found extremely premature newborns (especially less than 1000 g), children who require prolonged admission in intensive care units, patients with hemato-oncological diseases and patients who undergo precursor hematopoietic or solid organ transplants. Also children who have primary or acquired immunodeficiency, such as HIV infection or prolonged immunosuppressive treatment are at risk for IFI [1] [2] .

Histoplasma capsulatum is a fungus acquired by inhaling thermally dimorphic microconidia (environmental mold becomes yeast at 37˚C), produced by the micellar form. There are two biotypes able to infect humans: H. capsulatumvarcapsulatum and H. capsulatumvarduboissii.

In Latin America, the prevalence ranges from 2.1% to 20% and is defined as AIDS related event in 30% - 75% cases. Lung disease is the most common presentation followed by cutaneous diseases. Dissemination occurs in more than 50% of patients, and in these cases, up to 20% are co-infected with tuberculosis. More than 7% of all HIV patients in Guatemala manifest this infection in a disseminated way [3] [4] .

For the immunological diagnosis, the CD4 count is usually <150 cel/ul, although there is no threshold established in infants. It affects people immunosuppressed mainly by HIV, healthy infants from endemic regions <2 years, patients with rheumatological diseases under immunosuppressive therapy, children with acute lymphoblastic leukemia without neutropenia and patients after undergone a solid organ transplantation [5] [6] .

When IFI is in its disseminated form, the manifestations are nonspecific and systemic.

It is considered the most common endemic mycosis in the United States and Central America, causing localized epidemics related to environmental alterations such as exposure to bird droppings, bats and dust [7] .

Cryptococcosis is produced by Cryptococcus neoformans varneoformans, which is responsible for 95% of cases, and Cryptococcus neoformansvargattii, mostly observed inimmunocompetent patients. This infection is the second cause of death by fungi in Latin America. This yeast is encapsulated and is acquired by inhalation and affects patients with AIDS, transplant recipients, Sarcoidosis patients, chronic lymphoproliferative and auto immunedisease patients. It has also been described in children without immunodeficiency and patients without underlying disease up to 5% - 10% [4] [8] [9] .

The most common manifestation in Latin America is meningoencephalitis, and 85% of cases are produced by C. neoformans, of which, 80% are associated with HIV infection. Lung disease without dissemination is rare in children. This fungal infection can also affect lung, bone and skin tissues.

Coccidioides species include Coccidioides immitis in California, and Coccidioides posadasii in Arizona, Texas, Mexico, Central America and South America. In Central America, there are two endemic areas: the Motagua River Valley, Guatemala, and the Comaya Valley, Honduras. This dimorphic fungi, is acquired by inhaling the arthroconidia, which are spores that grow in warm soil in arid areas of the Americas. It is estimated that 60% of infected people do not develop symptoms or the symptoms are mild.

This infection is self-limited in more than 90% of children. Of those who do not limit the disease, 40% have flu-like symptoms, others could go up to disseminated infection (less than 5%), being immunosuppression a risk factor, even though it can affect healthy children. At lung level, it causes nodules and cavities (uncommon in children). Children with primary lung infection mainly may have fever, malaise, and chest pain, but it could affect bone and skin tissue, meninges and lymph nodes. In endemic areas, cough, fever, and cervical adenopathies are a useful triad for diagnosis [10] [11] .

The incidence of these fungi infections has decreased due to antiretroviral treatment, but they continue affecting HIV infected patients in regions where the diagnosis of viral and fungal diseases is insufficient. The three fungi are endemic in Guatemala. We elaborated this review because of the poor information available on these infections in children.

## 2. Methodology

This retrospective descriptive study was carried out in the pediatric department of the Roosevelt Hospital, a reference center in Guatemala.

The database of positive cultures from pediatric patients for endemic fungi of the microbiology department was reviewed. Data used was from 2007 to 2014, excluding diagnoses made by rapid tests. Enrollment was limited to pediatric patients (aged under 18 years) with newly diagnosed invasive fungi infection with medical records available.

The files were reviewed, focusing on epidemiological variables (gender, age and origin), clinical (predominant clinical manifestations and associated medical conditions), fungi (site of fungus growth) and laboratory data.

Qualitative variables were summarized using counts and proportions. Since data collected were considered as population-based, no hypothesis testing was conducted.

## 3. Results

1) Microbiological isolation:

For seven years, 23 isolates were documented:

a) Cryptococcus neoformans (12 cases)

b) Histoplasma capsulatum (10 cases)

c) Coccidioides sp. (1 case)

The study included ten patients with histoplasmosis, 4 with Cryptococcosis and 1Coccidioidomycosis case.

From the 12 Cryptococcus cultures, 8 of them, blood (1), cerebrospinal fluid (CSF) (3), urine (2), tracheal aspirate (1) and skin (1), were not included in the analysis because clinical data was not available.

2) Demographic data and associated medical conditions:

Table 1 shows patients characteristics, including the type of infection, age, and gender.

In the case of histoplasmosis, the average age was seven years old, and this infection occurred more in males (6/10).

Overall, 70% of the children were infected by HIV and one of them was coinfected by Hepatitis C virus (HCV). Other conditions were juvenile dermatomyositis under immunosuppressive therapy and two healthy infants with acute progressive disseminated histoplasmosis.

In the case of cryptococcosis, the average age was nine years old, and the distribution was equal in both genders. Two out of four patients with cryptococcosis had HIV infection. One of the patients had myelomeningocele and chronic renal failure and there was an infant with a urine isolation with no apparently underlying disease.

Regarding to coccidioidomycosis, there was a case in a 13-year-old girl with Down Syndrome.

Belonging the origin, according to regions of the country, more than half of the cases corresponded to central zone and south coast. Histoplasmosis cases had the widest distribution, although 90% of the cases were in the eastern, central and southern areas of the country.

Overall, distribution of infections was uniform throughout the country, especially in areas with tropical climate. There were no cases in the northern region.

SD = standard deviation, M = male, F = female, HIV = Human immunodeficiency virus.CRF = chronic renal failure.

Table 2 shows CD4 T lymphocyte count and basal viral load for HIV positive patients according to the type of fungus. From them, 89% were in stage 3 according to the CDC classification based on CD4 T lymphocite count. Only a one-year old infant was found in stage 2 [12] .

Regarding to viral load, patients older than ten years had values below100,000 cp/ml while younger children had higher viral load values. These patients were not on antiretroviral therapy because they were diagnosed with HIV along with the fungal infection.

3) Symptoms and signs

According to Table 3, the most frequent symptom was fever. It occurred in half of the cases of histoplasmosis and cryptococcosis. Other frequent symptoms of histoplasmosis were cough and asthenia. Dyspnea, headache, vomiting, diarrhea, and odynophagia, were less frequently observed, without predominance of a particular infection.

Regarding the clinical signs, we observed that adenomegaly, pallor, hepatosplenomegaly, exanthema, and wasting were the most frequent in histoplasmosis. Craneal hypertension occurred in cryptococcosis and the case of coccidioidomycosis presented suppurative adenomegalias without any other location.

4) Microbiological isolation site and affected systems:

Table 4 summarizes the isolation according to the type of sample and patient. Most of the isolated fungi were obtained from blood and bone marrow culture, collectively 7 (47%), ganglion biopsy culture 4 (27%), and CSF culture 2 (13%).

Histoplasma capsulatum was found primarily in blood culture and myeloculture in 7 patients, and ganglion biopsy culture in 3 patients. In one patient, urine and pleural fluid were isolated.

Cryptococcus neoformans was isolated in the cerebrospinal fluid of 2 patients infected with HIV, and in peritoneal fluid and urine. The only case of Coccidioides sp. was found in a culture of a cervical lymph node biopsy sample.

The infection by Histoplasma capsulatum did not affect a specific organ since in all (100%) of the cases was disseminated (all patients were immunosuppressed and healthy infants); Central Nervous System (CNS) was affected in 50% of

From al the patients, 53% did not receive any antifungal treatment due to the late diagnosis of the infection. This occurred in 50% of the patients with histoplasmosis infection and two-thirds of cryptococcosis infected patients.

Histoplasma capsulatum infection was treated with Amphotericine B with or without Itraconazole, for Cryptococcus neoformans infection, Amphotericine B and Fluconazole and for Coccidioides sp. was used Fluconazole.

One of the seven patients who received antifungal treatment died, and from the eight patients that did not received treatment, seven patients died.

**4. Laboratory Results**

1) Hematology:

Table 6 shows data obtained from laboratory analyses, according to age, sex, and infection. According to hematology data, patients were stratified by sex and age [13] .

More than a half (53%) of patients had leukopenia, 20% neutropenia and 73% of the patients had lymphopenia. More than 70% of children had anemia, and 33% had thrombocytopenia.

In general, more than 90% of the patients presented some hematological alteration, a decrease in some of the myeloid or lymphoid series. Lymphopenia and anemia were the predominant symptoms. Overall, children with HIV had lymphopenia (89%). According to the type of fungus, 70% of the cases of histoplasmosis and 75% of cryptococcosis had some hematological alteration.

WBC: white blood cells. Neut. Neutrophils. Lymph. Lymphocytes. Hb. Hemoglobin. HT Hematocrit. PLT platelets. GLU glucose. AF Alkaline phosphatase. LDH lactic dehydrogenase. ALT Alanine aminotransferase. ASAT aspartate aminotransferase.

The only case of coccidioidomycosis did not present important changes.

2) Blood chemistry:

Taking the normal value of alkaline phosphatase up to 270 UI/L, 46% of the children analyzed presented a high value. However, only one of the cases had a value greater than twice the normal value.

Taking 480 UI/L as the upper limit for lactate dehydrogenase, 58% of analyzed patients had an altered value. There was a 66% of altered results in criptococcosis infected patients and 63% of histoplasmosis infected patients.

Regarding to hepatic profile, 46% of patients presented an elevation of alanine aminotransferase (ALT) and 75% presented aspartate aminotransferase (AST) elevation.

From histoplasmosis patients, 66% of them had elevated ALT or AST values. All cryptococcosis cases presented ALT or AST elevation.

The only case of coccidioidomycosis did not present biochemical alterations.

**5. Discussion**

This study is the first one conducted in a reference hospital in Guatemala describing the characteristics of invasive fungal infections in the pediatric population. The total burden of serious fungal infections in Guatemala is unknown, but it is likely to exceed 268,363 cases (1.7% of the population), and cases reported in the pediatric population are not common [14] .

The incidence reported in the literature of endemic fungal infections in children is lower than in adults, in which HIV infection and reactivation of past infections are predominant risk factors. Due to the rapid progression and poor prognosis of these infections in the pediatric population and the difficulty of microbiological isolation, are generally underestimated [15] .

Although age range goes from 11 months to 14 years, there is a trend in children over five years old, especially in the case of HIV infected children (more than 65% are older than five years). These are children with slow progression of HIV infection that begins with reactivation of past infections, as occurs with adults. However, more than a third of the patients were under five years old, which indicates probable primary infection due to the endemicity of these pathogens in Guatemala.

The distribution by regions was uniform, due to tropical climate in the country and the predominant economic activity, consisting on agriculture and livestock, which favors the cycle of these fungi and high exposure to inocula. However, there is a trend

in the central and southeast region, perhaps because of the proximity to the hospital. There were no cases in the northern region. It is possible that the access from these cities to the capital makes it difficult to detect cases. Histoplasma capsulatum had the widest and most uniform distribution in many regions. Regarding frequency, the most isolated fungus was Cryptococcus, however, due to missing files; only 4 cases could be included in the study.

In general, around 80% of the patients had some disease related to the weakening of the immune system, as rheumatological disease, chronic kidney disease, and HIV infection (that occurred in 70%), and a girl with Down Syndrome. HIV infection was the most important risk factor for these infections [16] .

There is a possibility of these infections in children without underlying diseases, for example, there were two cases of progressive disseminated Histoplasmosis of the infant, a condition that may go unnoticed and be confused with other diagnoses. Furthermore, there were eight lost cases of Cryptococcosis infection that were not found in the HIV database, despite being a hospital where systematic HIV screening is performed on all patients that present these infections.

Pathogens were isolated from blood, bone marrow, lymph nodes, cerebrospinal fluid, peritoneal liquid, and urine. The yield of the culture of these samples could not be determined because it was not possible to analyze all the samples requested. Although the low profitability of the microbiological isolation for these pathogens is known, Histoplasma predominated in blood, bone marrow and lymph nodes due to its disseminated presentation, and Cryptococcus predominated in fluids, mainly cerebrospinal, due to the fact that more than 90% of cases with Cryptococcosis produce meningoencephalitis in patients with advanced HIV infection.

The optimal approach requires an early and accurate diagnosis to implement the appropriate antifungal therapy and minimize the use of toxic drugs. Standard methods as culture, histopathology and microscopy often lack sensitivity and specificity. These limitations have promoted the development of non-invasive diagnostics methods for fungal antigens or genetic material detection. Such is the case of galactomannan, 1 - 3 B, D glucan or Histoplasma antigen in urine by enzymatic immunoassay. However, the first two methods are not validated or standardized in children and they are not available in most countries with limited resources. However, Histoplasma antigen has a sensitivity of 95% in disseminated disease in patients with AIDS and can cross-react with Blastomyces dermatitidis, Paracoccidioides brasiliensis, Penicillium marneffei, Coccidioides immitis and Coccidioides posadasii [17] [18] .

The lack of specificity from clinical symptoms causes diagnosis and treatment delayed. Although more than half of the patients did not receive adequate treatment, mortality (which exceeded 50%) was higher in those who did not receive treatment. It shows a late diagnosis due to the nonspecific presentation of these infections and the difficulty of microbiological isolation. Another problem is the progress of opportunistic and underlying diseases (mainly HIV infection) since these patients are late diagnosed with HIV (89% of HIV patients were in stage three, and one was a stage two infant where the CD4 value is not predictive).

There should be caution when interpreting the CD4 T lymphocyte value in children < 5 years infected with HIV, as regards to its relationship with opportunistic

infections and the cut-off point, for example for histoplasmosis it is not defined, presenting qualitative alterations rather than quantitative. Furthermore, in children, the CD4 count to consider severe immunosuppression is different from that of adults. For example, two of the patients did not have CD4 < 150 which is the cut-off point for histoplasmosis in adults [19] .

Regarding to viral load, older children had values below 100,000 cp/ml, compared to young children, due to the natural evolution of the infection since younger children have higher replication of the virus.

In general, this situation of HIV and fungal infection in children in non-industrialized countries is common; being diagnosed at the same time, with no time for antiretroviral treatment administration.

In most of the cases, signs and symptoms were nonspecific, predominating fever and constitutional systemic signs with involvement of the mononuclear phagocytic system (hepatosplenomegaly, lymphadenopathy).

This supports isolation results, mainly in Histoplasmosis due to its 100% disseminated presentation. In the case of Cryptococcosis, the classic signs of CNS involvement were isolated from CSF in patients with HIV infection [20] .

The lack of specificity from the clinical findings causes the diagnosis and treatment to be delayed. Lab findings show decreased values of hematological parameters in these patients mainly for histoplasmosis and cryptococcosis. This is related to the presence of a secondary Hemophagocytic Syndrome [21] .

Anemia and lymphopenia are predominant, being the last one related to the depletion of CD4 T lymphocytes in patients with advanced HIV infection, caused by the late diagnosis.

The discrete elevations of alkaline phosphatase, lactic dehydrogenase and transaminases were observed in about half of the children. The AST/ALT index of 2.5 or greater, described as a contributor in the diagnosis of disseminated histoplasmosis compared to other IFAs, was observed in three children with this entity, but not in the others. These nonspecific findings should be considered in these infections, mainly in disseminated histoplasmosis [22] [23] .

The limitations of this study are that, as it is a retrospective study, some clinical histories were not available to be reviewed with the diagnosis of invasive fungal infection. The lack of some diagnostic techniques that are used today for these infections is also a limitation to our work.

In summary, in countries with tropical climates, such as Guatemala, there should be a higher index of suspicion of regional fungal infections in patients of pediatric age who present a situation of severe hematological cytopenias and neurological symptoms [24] .

Although infection by regional fungi can occur in immunocompetent patients, it is necessary to perform screening for immunodeficient patients, including HIV infection, since it is the most important risk factor for IFI in this population. The prognosis of the infection may depend on early diagnosis and treatment.

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# Seroprevalence and Risk Factors of Syphilis Infection among Antiretroviral Therapy

**Prince Asare-Bediako**

**Abstract** *Diagnosis of sexually transmitted infections is very important considering the spread of HIV and the extensive use of highly active antiretroviral therapy worldwide. This will assist in planning of treatment schedule in controlling these infections. The study therefore aimed at determining the prevalence of syphilis in HIV positive antiretroviral therapy naive patients in Cape Coast and the associated risk factors involved in infection. A cross-sectional study was carried out using initial HIV rapid and confirmation tests, and then Venereal Disease Research Laboratory test with the Ultra Rapid Test Kits for syphilis. Demographic data, risky sexual behaviours capable of co-transmission of both HIV and Syphilis, were also collected through the use of questionnaires. In all, 150 HIV positive antiretroviral naive subjects were studied and 15 (10%) were positive for VDRL test, with females (6.00%) and males (4.00%), who were mainly within the age group of 20 - 39 years. A significant number of males (p = 0.019) and females (p = 0.015) participants were not smoking with a fewer number of the females (p = 0.002) having multiple sexual partners. Also a smaller number of those who were infected with the bacteria (p = 0.004) did not support the control of sexually transmitted infection (p = 0.022). The result showed that co-infection of Syphilis in HIV positive antiretroviral therapy naive patients persists in the Cape Coast Metropolis, which is an indication of prominence of STIs that require further study on a larger scale to ascertain the extent of co-infection and to formulate policy for treatment to help minimize the rate of infection*

**Keywords:** Seroprevalence, HIV, Syphilis, Risk Factors, Antiretroviral Therapy

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Sexually Transmitted Infections (STIs) are of a major public health importance especially in the developing countries. Although several drugs are available for the treatment of the infections, it has been difficult to control as a result of the emergence of Human Immunodeficiency Virus (HIV) infection [1] . HIV infection severely weakens the immune system of infected individuals who are therefore exposed to opportunistic infections including sexually transmitted infections. The co-infection of sexually transmitted infections and HIV may be having a profound detrimental effect especially among the youth in developing countries. Syphilis and HIV appear to be the most reported STIs, although there has been a worldwide decrease in the prevalence of syphilis by the year 2000 [2] . The resurgence of cases of syphilis has been observed in the last decade [3] and about 357 million people aged between 15 and 49 are infected every year with Chlamydia, Gonorrhea, Syphilis, or Trichomoniasis with more than 95% of antenatal care attendees tested for syphilis [4] . It has been observed in previous years, that the rate of reported syphilis cases among men (15.6 cases per 100,000 males) was much higher than the rate among women (1.9 cases per 100,000 females), and men accounted for a large majority (88.9%) of syphilis cases [5] . Also 76.1 million people have become infected with HIV since the start of the epidemic [6] , and about 36.7 million people globally were living with HIV with 35.0 million people dying from AIDS-related illnesses since the start of the epidemic [7] . The development of both HIV and Syphilis infection in patients is complex and remains not well elucidated in spite of about 2 decades of clinical experience with co-infected patients. It has been established that primary syphilis facilitates both the transmission and acquisition of HIV infection [8] [9] . However, the relationship between the two infections among individuals is a concern.

In Ghana, data on population about HIV and Syphilis are very scanty. A few studies carried out on syphilis and HIV in some part of the country such as among truck drivers at Tema metropolis showed the prevalence of 3.8% and 0.98% respectively [10] . The prevalence of HIV and Syphilis infections and the associated factors among blood donors in Koforidua also showed 4.5% and 15.3% respectively [11] . There were also the seroprevalence of syphilis (8.2%) in blood donors at Komfo Anokye Teaching Hospital [12] . Again the prevalence of syphilis and HIV among prison inmates and officers at Nsawam and Accra was 16.5% and 5.9% respectively [13] . Nevertheless, recent data by the National AIDS Control Programme, a body responsible for carrying out sentinel survey of communicable diseases in the country showed the national syphilis prevalence rate of the country to be 0.2% [14] . This is an indication that syphilis infection is nationwide and may be high in urban areas since these areas are highly populated with economic and social activities.

Recently, Ghana has shown the Central Region as the leading region in syphilis cases in the country. And the sentinel report presented by Ghana AIDS Commission in March 2012 showed that Cape Coast had 9.6% of HIV prevalence, being the highest in the country [14] . The high rates of infection of these two diseases suggest a notable evidence of co-infection among individuals, which is definitely affecting the economy in terms of reducing productivity. There is also reduction in the normal health states of population rendering it dangerous to live in some parts of the country. The main

objective was to determine the prevalence of syphilis and the associated factors in HIV positive but antiretroviral therapy naïve patients in Cape Coast metropolis.

## 2. Methods

### 2.1. The Study Area

The study was carried out at the Cape Coast Teaching Hospital where majority of people visit for Medical care. The teaching hospital is a 400 bed facility in the Central Region of Ghana and the main referral hospital that serves the Region as well as parts of Western and Ashanti Regions. It also provides facilities for the training of medical personnel such as doctors and nurses from the University of Cape Coast. It has HIV clinic which has been providing services for patients since 2006.

Cape Coast is the capital town of the Central Region which has a settlement population of about 169,894 [15] . Vegetation of the study area (Cape Coast) is mainly secondary forest with thickets and shrubs growing to an average height of 4.5 m. There is also a coastline which is about 13 km long. Cape Coast is a humid area with mean monthly relative humidity varying between 85% and 99%. The sea breeze has a moderating effect on the local climate. The metropolis is bounded on the east by Abura-Asebu-Kwamankese District, West by Komenda-Edina-Eguafo-Abrem District, and south by the Gulf of Guinea and north by Twifo Heman Lower Denkyira District. The city is one of the communities within the metropolis along the southern coast, and as such, fishing is one of its major economic activities. The Cape Coast Metropolis is the central focus of tourism in the region. Within the Metropolis are many sites and attractions of scientific, historical and aesthetic importance that help to boost economic status of the metropolis, region and country at large. In spite of these, Cape Coast has an unemployment rate of 13% with unemployment affecting females more than males.

### 2.2. Study Design

The research was a cross-sectional study with questionnaires designed by the corresponding and the first authors to elicit some information from the study participants. The questionnaires were pretested on patients at Ewim District hospital, also at Cape Coast. After a few modifications, the questionnaires were administered based on the validity and reliability. There was actually no conflict of interest, with a well-structured closed-ended questionnaires administered to the HIV-positive antiretroviral therapy naive patients who were yet to be put on antiretroviral therapy. The demographic information obtained with the questionnaires was age, sex, occupation and level of education. Other variables obtained were, engagement in some risky behaviour such as smoking, drinking of alcohol, and having multiple sexual partners; and reactions towards health care given to them in the hospital laboratory.

### 2.3. Ethical Consideration

The study had approval from the Institutional Review Board, University of Cape Coast and the Cape Coast Teaching Hospital authorities. A verbal consent, as well as written informed consent was also sought from the participants of the study, after the procedures were clearly explained. Results and records were strictly kept confidential.

### 2.4. Sample Collection

Blood samples were collected from 150 HIV infected patients who visited the Out Patients' Department of the Cape Coast Teaching Hospital. These patients were already

diagnosed to be HIV positive and yet to be put on antiretroviral drugs. About 5 mls of samples were collected with JMK Hypodermic syringes into P-Smart sterile EDTA tubes, and spun in the centrifuge to get the plasma for the various tests. All samples were assigned codes in order not to mix them or use for repeated data. The samples were tested for HIV with Rapid test kits and confirmed by ELISA as described by Baah et al. [16] [17] . Briefly, the plasma was reconstituted and mixed with the selenium colloid-antigen conjugate. A drop of the mixture formed was added to a spot on the strips to migrate through the solid phase to the antigen immobilized recombinant antigens and synthetic peptides at the patient window site. Antibodies to HIV-1 and/or HIV-2 present in the sample bound to the complex of antigen and antigen-selenium colloid conjugate forming a red line at the patient window site. However, the absence of antibodies to HIV-1 and/or HIV-2 allowed the antigen-selenium colloid moved past the patient window site, and no red line was formed. Also for the ELISA, a recombinant antigenic proteins and synthetic peptides from HIV-1, HIV-2, and HIV-1 group O were coated as discrete lines on a nylon strip with plastic backing. Plasma samples were incubated in a test trough together with the multiple antigen-coated test strips. HIV antibodies in the samples, bound to the individual HIV antigen lines on the strip. Afterwards, a goat anti-human IgG labelled with alkaline phosphatase was added to bind to any HIV antigen/antibody complex previously formed and incubation with the enzyme substrate (BCIP/NBT) produced a dark brown colour in proportion to the amount of HIV antibody present in the samples. Colour development was stopped with sulphuric acid. Samples containing no HIV-specific antibodies, the labelled antihuman antibody did not bind to antigen/antibody complex so that only a low standard background colour develops.

Syphilis test (VDRL) was carried out on HIV positive samples as described by Faustina et al. [18] . Briefly, the plasma was heat inactivated at 56˚C for 30 minutes and diluted to 1 in 20. Samples were kept at room temperature for 30 minutes. About 25 µL aliquots of plasma and 75 µL antigen coated test cells, in a final dilution of 1to 80 were transferred to U type microtitre plates examined for 4 hrs incubation at 25˚C. A final reading was made after overnight incubation. Results were recorded as follows: Negative—A smooth ring or button of cells. Positive—A diffuse carpet or a thin ring of cells with marked agglutination. Weak positive—A slightly enlarged ring of cells with peripheral agglutination.

2.5. Statistical Analysis

Data was entered into Microsoft Excel and statistical analysis was carried out using Statistical Package for Social Sciences (SPSS version 17, inc Chicago). Differences among participants groups (age, gender, occupation, marital status, risky sexual factors, and laboratory satisfaction) were analysed using Chi-square goodness-of-fit and fisher exact test. Collective co-efficient was calculated for variable of interest and the significance level set at 0.05.

## 3. Results

Syphilis appears to be quite high in the Central Region of Ghana and out of 150 HIV positive participants tested, 15 (10%) were positive for the disease. In relation to their demographic factors, Table 1 showed the age groups, sexes and marital status of the subjects involved in the study. It can be found that 10 (6.67%) of the participants

within the age group 20 - 29 and 30 - 39 years were infected with syphilis. These were followed by 40 - 49 and 50 - 59 age groups with 2 (1.33%) each. There was no trace of Treponema palladium antibodies in the samples of participants in the age groups below 20 years (0%). Therefore, the prevalence is significantly higher among 20 - 29 and 30 - 39 age groups in HIV positive antiretroviral therapy naive participants in Cape Coast ($p = 0.026$) than the other age groups.

Among males and females it was noted that 6 (4.00%) of the males had the traces of syphilis antibodies, similarly females who were infected were 9 (6.00%) ($p = 0.828$). Eighty (53.33%) of males, and 70 (46.67%) of females, were not infected with the bacteria.

Again, the prevalence of syphilis in married patients was 6 (4.00%) and was similar in unmarried, 9 (6%), participants, ($p = 0.828$). Also 86 (57.33%) of the married participants were not infected, just as 64 (42.67%) of the unmarried participants were also negative to the infection.

HIV infected individuals in Cape Coast. Nevertheless, the prevalence of syphilis among the HIV patients in this study was lower than that of HIV positive antiretroviral naive adults attending APIN Clinic at Lagos University Teaching Hospital, being 20% [21] and more so in co-infection of Syphilis and HIV in Port Harcourt, Nigeria, being 33% [22] . It is therefore likely syphilis is a common opportunistic infection among HIV infected patients when they do not take precautionary measures in their sexual practices.

In addition, the infection was high among the youth ages between 20 - 39 years. This is not surprising because youths of these age groups are sexually active and may be having more than one sexual partner. However, it was noted that a significant number of participants were not smoking, drinking or having multiple sexual relation. These suggest the above factors may not be exposing individuals to syphilis infection in the community.

The promiscuous behaviour of women in the society may be due to economic hardship especially among the young ladies who may be indulging in sexual activity for their livelihood. This assertion is supported by the fact that more females HIV infected patients were also infected with syphilis as compared with their male counterparts. Syphilis infection may be subclinical in females for a long time and that makes them spread the disease without knowing that they are infected. Unlike the females, majority of the males develop symptoms in early stages of infection and therefore seek medical attention [23] . More so, it has been proven that HIV positive patients have higher risk (3 - 5 folds or times) in contracting other sexually transmitted infections if one engages in multiple sex practices [24] [25] . Again, it has been noted from the study that more of the males are engaged in having multiple sexual partners compared to the females. However, more females were infected with both HIV and syphilis infections suggesting they may be actually having multiple sexual partners but did not disclose that in their questionnaires. Taking of alcohol and smoking are also a significant risk factors associated with STI infection. From the study, a few of both males and females were involved in smoking as well as taking alcohol supporting the fact that this did not contribute much into the acquisition of syphilis infection in the community.

Even though the males were of higher proportion as compared to the ladies they appeared to be protecting themselves against STI when engaging in sexual acts [20] . This may be due to the fact that more visible expression of symptoms of syphilis occurs in male genitalia as a compared to the female genitalia [23] and therefore the males are cautious in their sexual activity. Education is also important in creating awareness and control of syphilis/HIV infections, but it did not play a significant role in the rate of the infections.

Majority of infected participants recommended syphilis test within the community but they did not support the control of sexually transmitted infections among couples in relationship. This could be the fear of being known as infected participants and subsequent loss of sexual partners. Smoking, alcohol intake and multiple relations are known predisposing factors leading to infection of most sexually transmitted infections including syphilis [26] . This study has shown no association between these factors and syphilis. It is likely HIV might be the main factor that is contributing to the high prevalence of syphilis as recently noted in the Central Region of Ghana in which Cape Coast is the capital.

Majority of the participants including syphilis-infected patients were generally satisfied with the entire processes in the laboratory. However, smaller number of them was satisfied with the awaiting time at the hospital's laboratory, which is not encouraging at all. This can deter people from coming to the laboratory voluntarily or if the person feels he or she is healthy. Again those participants, who were negative for syphilis, may not be willing to attend the hospital for any laboratory check-up, if they contract the infection after their experienced with this laboratory session. Eventually, some members of the population may be harboring the bacteria for a longer time and will aid in spreading the bacteria among others, leading to shorter life expectancy or neurologic involvement [20] . It was noted that some of the participants complained of unfriendly reception and delay in services. Solution to these complaints is very necessary in promoting the good attitudes of members of the Cape Coast Metropolis in engaging in regular laboratory tests for STIs, thereby tracking the syphilis infection in its infectious stages [19] . Also further detailed studies may help understand the relationship between these infections among the youth of the population in the metropolis.

## 5. Conclusion

In conclusion, the prevalence of syphilis in HIV positive antiretroviral therapy naive patients in Cape Coast is high and common among age groups of 20 - 39 years of the population. This is of great concerned since the youth are the back bone of the economy in the country and should be encouraged to lead sexually moral life.

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# Trends of HIV Viral Load in Patients under Combined Antiretroviral Treatment in Bangui

**Alain Farra**

**Abstract** *Background: The success of antiretroviral therapy requires better virological monitoring. We described the virological profile of patients on combined antiretroviral therapy (cART) for HIV/AIDS in Bangui, Central African Republic (CAR). Methods: In this prospective cohort study of patients who had been on combined antiretroviral therapy treatment (cART) for at least 12 months in Bangui, only one HIV plasma viral load per patient was realized at the Institut Pasteur of Bangui, between April 4th and November 28th, 2017. Sociodemographic and biological data were collected. Blood samples were taken for viral load. The biocentric generic human immunodeficiency virus (HIV) load test was used to quantify a ribonucleic acid (RNA) HIV-1. Data were analyzed with Stata software version 14. Chi-squared test was used to analyse viral load according to sex and age. The level of significance was set at* $P \leq 0.05$. *Results: A total of 3569 patients were recruited, with a mean age of 40 years (median, 42 years; range, 1 - 84), patients aged 40 - 49 predominating (34.2%). The sex ratio was 0.4. No virus was detectable in plasma from 49.2% of patients, while 42.4% had virological failure (viral load, ≥1000 copies/mL) according to WHO criteria. The risk for virological failure decreased with age (*$P = 0.001$*) and was higher among females than males (*$P = 0.001$*). Conclusions: The rate of virological failure among patients on cART is very high in the CAR, despite the availability of and access to monitoring of HIV plasma viral load in Bangui. Therefore, adherence to treatment should be evaluated and reinforced in Bangui, CAR.*

**Keywords:** *Plasma Viral Load, Failure, HIV-1, Bangui, CAR*

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## 1. Introduction

The Central African Republic (CAR), landlocked country has undergone a decade of socio-political instability, which has led to a humanitarian crisis and a weakening of the country's health system. The Global Fund to Fight Acquired Immunodeficiency Syndrome (AIDS), Tuberculosis and Malaria and other partners have been worked with local authorities to strengthen the health system and to address the diseases of the century, especially human immunodeficiency virus (HIV/AIDS). In 2010, the prevalence of HIV infection was 4.9% among adults aged 15 - 49 years old throughout the country and 7.7% in the capital, Bangui [1] . In 2015, the national center for monitoring internal displacement reported that 368,859 people were in informal camps [2] . In December 2015, in view of the precarity and vulnerability of the population, 18,250 patients with HIV infection received emergency stocks of 3 months of antiretroviral therapy (ART) [3] , which were renewed frequently. With controling and sustaining rapidly, the multiplication of the virus decreased and immunocompetence restored.

Therapeutic success depends on close monitoring from initiation of treatment and over time. Biological and clinical follow-up after 12 months of treatment is essential to evaluate antiretroviral therapy (ART) and to detect HIV resistance [4] [5] . In 2015, the World Health Organization (WHO) recommended that the monitoring of patients on ART should include CD4 cell counts and measurement of HIV plasma viral load; virological failure was defined as a viral load ≥ 1000 copies/mL [6] [7] [8] . In practice, the viral load is estimated from the number of copies of ribonucleic acid (RNA) HIV-1 per milliliter of plasma, determined with commercial molecular technic used to evaluate the effectiveness of ART.

In 2017, with the support of the International Federation of Red Cross and Red Crescent Societies, the Institute Pasteur of Bangui (IPB) proposed the measurement of HIV viral load and other biological tests for the monitoring of people living with HIV (PLWH) were taken in charge. The objective of this study is to describe the virological profile of patients receiving antiretroviral therapy in CAR.

## 2. Patients, Materials and Methods

### 2.1. Type of Study, Duration, Inclusion or No Inclusion Criteria and Respect for Anonymity of Patients

In this prospective cohort study of patients in Bangui, who have been on ART for at least 12 months, consisting in 1st line regimen as recommended by 2013-revised World Health Organization (WHO) recommendations [8] , only one viral load per patient was realized to IPB, during April to November 2017. The IPB is a charitable public institute working by agreement with the Government in the CAR since February 1961. The main activities of the institute are biomedical research, public health support and training. The research is oriented towards public health, providing information to the local health authorities on emerging and neglected diseases such as Buruli ulcer. It also participates in field studies during epidemics (rabies, yellow fever and arboviruses diseases such as dengue) and works with national programs, against poliomyelitis and measles. The institute has a medical analysis laboratory, which provides services for the entire population of the country, including biological monitoring of people living with HIV (PLWH). Inclusion criteria for this study were

followed: antiretroviral therapy since at least 12 months, consisting in 1st line regimen as recommended by 2013-revised WHO recommendations [8] ; availability of simple demographic data of patients (age, gender), treatment history (duration), informed consent from patients or tutors. We excluded from this study: HIV-infected patients who were on treatment for less than one year and patients infected with HIV-2. In this study using clinical files and electronic registers, the patient's identity was not collected in the survey file to ensure ethical clearance.

2.2. Sample, RNA Extraction and Real-Time Polymerase Chain Reaction Amplification

A blood sample was taken from all patients for quantification of RNA HIV-1 into a tube with ethylenediamine tetraacetic acid (EDTA), and the plasma was divided into aliquots and stored at −20˚C until doing RNA extraction according to manufacturer's procedures. Biocentric RNA HIV extraction kits (12.08.02 - 170,510) and automated methods using NorDiag Arrow extractor (AO637R3) have been used for HIV-RNA extraction. Biocentric RNA HIV amplification kits (TR001-250IC) was used for real-time PCR on Applied Biosystems QuantStudio™5 (A28133). The target region was on the long terminal repeats (LTRs), and the detection limit was 390 copies/mL. The technic is specific for HIV-1 group of M sub-types A-H.

2.3. Statistical Analysis

Data were entered onto Excel® sheets and analyzed with Stata software version 14. The data included the sex and age of patients, and viral load, categorized as <300 (virological suppression or undetectable). The viral load was presented as <1000 copies/mL (virological success) and ≥1000 copies /mL (virological failure). The World Health Organization (WHO) guidelines recommend the use of viral load as the preferred method for monitoring treatment response over clinical and immunological approaches, and define virological failure with a threshold of 1000 copies/mL [7] [8] . The analysis was performed on all data from included patients (exhaustive sampling). Chi-squared tests and odds ratios with 95% confidence intervals (CIs) were used to analyze viral loads according to sex and age. The level of significance was set at $P \leq 0.05$.

## 3. Results

The viral load of 3569 patients was measured during the study period. The mean age was 40 ± 13 years, with a range of 1 - 84; most of patients (34.2%) were in the age range to 40 - 49 years old (Table 1).

Table 2 shows the distribution of patients by detectable HIV viral load and undetectable HIV viral load by age group and sex. The number of patients with a detectable viral load was inversely related to age, with significant differences from those with no detectable virus in each age group. Significantly more female (51.1%) than male patients aged 40 - 49 years has no detectable virus (Table 2).

More female patients (59.4%) than male patients has undetectable HIV viral load, where as more male patients (46.8%) has virological failure. Nevertheless, almost every other patient showed virological failure.

Comparison of patients with and without virological failure by age group showed statistically significant differences (Table 3).

## 4. Discussion

We observed a preponderance of women, with a sex ratio of 0.4, and a median age of 42 years. These results are similar to those of Mouala C et al. [9] , who found a sex ratio of 0.4 and a median age of 32.5 years in a study of factors associated with adherence to treatment among HIV-infected patients in Bangui in 2006.

At a detection level of 300 copies/mL of blood plasma, 49.2% of patients had an undetectable viral load (virological suppression). This rate is lower than those found elsewhere, such as 83.3% in Benin [10] , 84% in Morocco [11] and 96% in the west part of the Ile de France (Paris region) [12] . The low rate in the CAR is due to the unstable sociopolitical situation in the country, which has complicated geographical access to treatment and the monitoring of patients. HIV viral load is more available and more accessible in the capital, Bangui, in view of the cost and technical requirements of the test. Samples have taken into tubes containing EDTA, which must be maintained at 4˚C and transferred rapidly to the laboratory four hours after the collect. An alternative to this system would for regional health centres to send dried blood spots (DBS) on filter paper for analysis centrally. In this way, all the regions of the country would have access to early measurement of HIV viral load [13] [14] [15] [16] [17] . Patient's adherence to treatment could also be evaluated and strengthened in order to increase the rate. The adherence rate measured about 10 years ago in Bangui was 77.5% [9] . Regular measurement in routine practice could increase the rate.

The fact that 42.4% of patients are virological failure could result in therapeutic failure for nearly half of all our patients. Virologic failure has often been described and associated with therapeutic failure in the country. In 2012, Pere H et al., according to the 2010 WHO guidelines, observed in RCA, in 386 adult patients on first-line antiretroviral treatment for 24 months, a virological failure in 28.5% (HIV-1 RNA > 3.7 log (10) or 5000 copies/ml). Twenty-four percent of patients in virological failure showed wild-type viruses, likely indicating poor adherence. Even after excluding the M184V mutation, 76% of patients in virological failure displayed viruses harboring at least one major drug resistance mutation to nucleoside reverse transcriptase inhibitors (NRTI), non-NRTI, or protease inhibitors [18] . Moussa S et al., have also studied the emergence of resistance mutations in isolates from CAR patients at failure of d4T-AZT/3TC/ NVP-EFV, the resistance mutations observed are those which are expected on HIV-1 subtype B [19] . These observations point the necessity to monitor patient receiving regimen by plasma HIV-1 RNA load to diagnose situations of therapeutic failure and to operate switch. The same finding was made in children after 18 to 30 months of ARV treatment by Charpentier C et al. in 2012, who found a detectable viral load in 53% of children, 40% of whom were virologically failed (HIV-1 RNA > 3.7 log (10) copies/ml) [20] . Mossoro-Kpinde CD et al. in 2016 had been found in children under 5, on first- and second-line antiretroviral therapy, who have a detectable viral load, a virological failure of 97% [21] . With untreated young children living in the CAR, Charpentier C et al., found that 66% of them showed plasma HIV-1 > 1000 copies/ml and were in virological failure, according to the 2015 WHO guidelines [22] .

Monitoring of patients is important to ensure that the treatment is effective and their health improves, and therapeutic follow-up requires measuring the viral load, which is the main biological method for identifying and confirming virological failure. If viral load cannot be measured routinely, diagnosis of therapeutic failure is based on

the CD4 cell count and clinical follow-up, with, when possible, targeted measurement of viral load to confirm the diagnosis [6] . Virological failure, indicated by a viral load above the threshold of detection, should be confirmed by successive sampling and differential diagnosis of a “blip” (virological extrasystole), non-adherence or stopping treatment. The importance of the difference between the limit of detection and the threshold of 1000 copies/mL has been discussed in a number of studies. Nevertheless, the quantifiable viral load should be monitored, as low viremia can lead to virological failure and then to therapeutic failure or the emergence of mutant viruses that are resistant to ART [17] [23] [24] [25] [26] [27] .

More female than male patients have an undetectable viral load (51.1%), and more female patients (59.4%) showed virological success, as reported elsewhere [9] [10] . The risk of female patients for a detectable viral load was significantly lower than that of male patients. Female patients adhere more closely to their treatment than male patients, as they learn the importance of adherence during perinatal visits and attend health centers more frequently, where medical personnel reinforce the message. Men have poorer adherence either because they forget, are too busy or do not wish to take their drugs. The probability of having detectable virus decreases with age. Difficult access to paediatric forms of ART and the behavior of adolescents may explain their high rate of virological failure; with age, patients are more aware of their condition and the importance of good adherence to treatment [9] . The predominance of heterosexual, vertical transmission in tropical regions, particularly in sub-Saharan Africa, may explain the prevalence of the disease in this age group [10] [28] .

Sociopolitical disturbance, the distance to treatment centers, treatment with several drugs and their side-effects have all been reported to contribute to poor adherence to ART [9] [10] [29] [30] . Measurement of viral load is essential in order to diagnose the rate of therapeutic failure and to strengthen treatment adherence. In view of the situation in the CAR, some patients may have been lost to follow-up or have had to interrupt their treatment. Better access to viral load measurement could improve the management of patients on ART in the country.

The accessibility of HIV viral load is still improvable in the CAR. The limitations of this study relate to other biological parameters of the follow-up that were not sought. Immunological and hematological parameters are also determining factors in the therapeutic evaluation of patients on cART. But given the size of this study and its objective, these parameters were not studied in all patients so not reported. This study, however, updated the virological profile data for a large proportion of patients on antiretroviral therapy and described the trends in HIV viral load by age group and sex. Other studies will deepen the question of the multidisciplinary management of patients under treatment in the CAR.

## 5. Conclusion

HIV viral load is more available in Bangui. Virological failure was observed in 42.4% of patients, while 49.2% had undetectable virus. The high rate of virological failure associated with immunodeficiency could result in therapeutic failure. It is therefore essential to strengthen monitoring of treatment adherence and improve access to measurement of viral load in Bangui, CAR.

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# An Assessment of Quality Assurance in HIV and AIDS-Related Services in Chivuna Rural Health Facility of Southern Zambia

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**Abstract** *With many countries experiencing high prevalence rates of HIV scaling up ART, it is vital to assess quality assurance in health facilities accredited to pro-vide these HIV and AIDS-related services. Reviewed literature indicates that there are limited studies in Zambia on the capacity of accredited health care facilities to provide effective HIV/AIDS related services. Using data from a large ethnographic qualitative study in a resource poor rural setting in Zam-bia, this paper assesses quality assurance in health facilities to providing HIV/AIDS services in a remote rural setting. Findings show that although HIV and AIDS related services were available at the remote rural health facil-ity of Chivuna, the services provided did not meet the WHO minimum guide-lines/standards on the provision of such services. Therefore, there is need for such facilities to be adequately equipped in all the departments of ART deli-very so as to ensure effective delivery of these services and universal access.*

**Keywords:** Zambia, HIV and AIDS, WHO Guidelines, Capacity of Health Facilities

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## Introduction

Like many other countries with grappling with relatively high (13%) prevalence rates of the HIV and AIDS pandemic within the Sub-Saharan Africa, Zambia has scaled up HIV/AIDS-related services. In this regard, the government of the Republic of Zambia has accredited a number of health centers to offer HIV/AIDS-related services so as to maximize accessibility as well as monitor the quality of services offered to the population. Inadequate literature, however, exists on the capacity of these facilities to offer HIV/AIDs-related services in line with the key principles underpinning the

accreditation framework of health care services for people living with HIV/AIDS [1] . This is the gap in knowledge that this paper attempts to fill.

The World Health Organization (WHO) posits that quality assurance is premised on a structure-process-outcome framework. This means that it has an objective of improving the outcome of a broad spectrum of health care in terms of health, functional ability and the well-being and satisfaction of health care users [1] [2] . The main purpose is to get everyone involved in health care provision to take an active role in supporting quality care, intensifying performance-related problems and taking responsibility for setting in motion the needed changes to improve care.

In the 2004 report of a consultation meeting on the accreditation of health care service facilities, WHO stipulated guidelines for quality assurance in HIV care. The guidelines were not meant to be blueprints of care but were to be adopted according to member countries' capacity and prevailing social environment. In Zambia, the guidelines include issues related to HIV counseling and testing, human resource, physical infrastructure, supply of ARVs drugs and laboratory management [3] [4] and it is against these that this paper assesses the research site.

The guidelines stipulate that a facility offering HIV and AIDS-related-services should have an established policy and follow a written policy on HIV testing. This policy should reflect national laws and WHO guidelines for rapid testing [2] . Additionally, all staff should be familiar with the policy. In terms of counseling, there should be both pre-test and post-test counselling and HIV testing should be conducted with informed consent by individuals trained for the task. The counselling should take place in an environment that ensures privacy. Testing should adhere to 5 Cs of consent, confidentiality, counselling, correct results, and connection to care, treatment and prevention services [3] .

In terms of human resource, a facility should have an ART Clinical Officer (CO) permanently located at the ART clinic, two nurses—one for drug dispensary and the other for adherence, 4 community adherence supporters and data entry specialist/health communication officer. All members of staff working in such a facility should be adequately trained and certified to prescribe ART, follow up recipients clinically and also be able to handle HIV and AIDs related issues and conditions that may confront them [2] . This includes both adult and pediatric ART.

Such a facility should have at least six rooms consisting of a screening room, registry room with secure and confidential patient record system with lockable cupboards. In addition to this, there should be a special counselling room, waiting room, information room and dispensing room with stock control cards and air condition to keep the drugs at the right temperature.

Uninterrupted supply of ARVs and ART provision is also one of the standards. This was meant to promote adherence to ART [4] . There is also need to support people being treated so as to facilitate their adherence to the prescribed treatment and a written protocol to guide decisions on treatment eligibility.

Laboratory management should include rapid testing, a CD 4 count machine for viral load monitoring, and hematology machine, full serum chemistry analyzer, mycobacterial culture, sputum smear microscopy for TB detection, hemoglobin and HIV antibody test machines [1] [2] [4] . Additionally, the laboratory should meet

National Guidelines and tests norms or WHO guidelines. In terms of clinic frequency or opening times, the clinic should be provided at least five days in a week.

In sub-Saharan Africa, a number of studies have been carried out to assess the quality of care and capacity of health facilities accredited to provide HIV-related treatment in resource-limited settings [5] [6] [7] [8] . Although these studies have reported positive out looks in a few health facilities, they have largely shown inadequacies in the health delivery system. The studies for instance indicated that there were inadequate trained personnel in HIV and AIDS related services and ART management [5] [8] inadequate laboratory equipment for ART monitoring, inadequate confidential places for counseling and information system was weak [5] [9] . Others were the inability of all the eligible patients to start ART due to inadequate ARVs and persistent drug stock-outs [6] [7] [8] .

In Zambia, reviewed literature indicates that there are no studies done to assess quality assurance among accredited health facilities. The extent to which accredited health facilities are suitable to offer HIV-related services is thus unknown. This article reports findings from a study that was conducted in the rural site so as to profile the characteristics of health facility from a resource constrained country but also a rural one where conditions are expected to be in worst shape.

## 2. Methods

2.1 Study Area

The study was carried out in Chivuna, a rural community located approximately 60 km South-East of Mazabuka town, 35 Km from the Great North Road and about 70 km South of Lusaka, the capital city of Zambia. The main ethnic group is the Tonga speaking (or Ba-Tonga in plural), a matrilineal and patrilocal group of people. Chivuna has a population of approximately 19,000 scattered in an area covering about 34 square kilometers. The main source of livelihood is subsistence farming, which is seasonal and dependent on the rainfall pattern. Like most rural areas in Zambia, poverty levels are high, averaging more than seven people in ten being poor and having limited access to basic necessities, including food, shelter and health care. While nearly all the health facilities in the area offer VCT, ART services only exist at Chivuna and Mbayamusuma health facilities. The two facilities have a distance of more than 40 km apart. Chivuna health facility started providing VCT and ART in 2006 and 2008 respectively.

2.2. Data Collection and Analysis

The data presented here was part of a bigger qualitative, ethnographic study conducted over a period of one and half years. This component of the study assessed quality assurance at Chivuna facility being one of the health facilities accredited to provide ART in the District. The facility was visited several times over the study period. In-depth interviews with professional and lay staff, Focus Group Discussions (FGDs) and observations of available resources were conducted. A total 8 professional health care providers, 6 community health workers and 10 ART clients were interviewed. FGDs were conducted with ART clients where there we had 2 from the health facility and the other 2 from the community. Observations were done with respect to staffing levels, available space, essential equipment, drug supplies, laboratory systems and patient-provider interactions/relationships among others. Interviews with health staff

were conducted in English while those with community members were done in the local language, Chitonga. Purposive sampling was used to recruit all study participants.

For the purpose of quality control, all the interviews and observations were carried out by the principal investigator. Repeated observations were conducted at the health facility. All interviews were transcribed verbatim and word-processed and the analysis was done using Atlas-ti version 7 using grounded thematic coding, starting with open coding after which all the codes were grouped into similar categories. From these categories, themes were generated.

2.3. Ethical Approval

Ethical approval for the study was obtained from the Research Ethics Committee of the school of medicine at the University of Zambia and it was also cleared by the Ministry of Health. For all the individuals that took part in the study, informed consent was administered and participants were made to sign and for those who could read or right thumbprints were used. Before consenting, each participant was asked if they understood the risks and benefits of taking part in the study. Anonymity and confidentiality were assured by way of not disclosing actual identities of participants in the interview tools and subsequent publications.

## 3. Results

The assessment quality assurance addressed questions related to HIV/AIDs services offered and where were they located, when they were administered, who was in charge of the administration and under what conditions. Focus was also on the infrastructure, staffing levels, training of staff who administer ARVs, the availability of essential drugs, reagents and equipment such as CD4 count and liver functioning machine. The results are reported are reported with respect to these parameters:

3.1. Provision of VCT and ART Services

Chivuna Rural health facility offers both VCT and ART services. The facility has been providing VCT and ART services since 2006 and 2008 respectively. These services were provided three times per week on Mondays and Thursdays (with Wednesdays restricted for pediatric ART). ART was not integrated into general health services but was separated from the rest of the services. This practice was to some extent viewed with mixed feelings by some clients. While some felt that it exposed them to finger pointing and stigmatization, the majority seemed to hold a few that it was better as it gave them an opportunity for interaction and to share experiences among themselves as fellow positive people. Such experiences were viewed as facilitating factors for adherence. There was a TB and youth-friendly corner though at the time of the study the youth friendly corner was not yet in operation. This seemed to create a lot of challenges for youths who were visibly missing from the facility.

The health facility was also involved in provision of mobile services which included VCT and community-based sensitization. This was done in order to provide services to many remote communities, which were still affected by long distances to health centers. These mobile services were provided with the support of NGOs such as Churches Association of Zambia (CHAZ) and Total Control of the Epidemic (TCE) a Danish funded NGO. The main services offered under the mobile services were Prevention of Mother to Child Transmission (PMTCT), under five clinic, antenatal clinics, community sensitization, family planning and VCT. CHAZ had also bought the

facility a 4 × 4 vehicle specifically for mobile VCT. However, provision of these community-based activities was at times not consistent due to inadequate and erratic funding as well as shortage of staff. For instance, although the health facility had more than two vehicles, with one vehicle specifically for the ART clinic, the whole facility only had one driver for all the duties at the center. At times fuel was not available. These limitations were ably presented by one of the male health care providers working at the ART clinic when he elucidated:

The available number of staff is at times inadequate to go out in the communities to carry out outreach programs such as community sensitization and mobile ART services because we now have two clinics to run yet the number of staff has remained the same. The same members of staff who work at the ART clinic also conduct general health services. We are also supposed to have two drivers but we only have one at the moment, so it is quite difficult for us even if we have a vehicle specifically meant for the ART clinic. Sometimes you find that you arrange to go out for sensitization or to do mobile ART services, but in the meanwhile there are other operations somewhere that need a driver, or maybe there is an emergency. This means that we have to abandon whatever other activities we had planned.

The hilly and rugged terrain of the area and generally poor state of the road network made some communities inaccessible particularly during the rainy season. For TCE, this was confounded by the use of bicycles as the main mode of transport. However, even when a 4 × 4 vehicle was available; some areas were still not accessible by such kind of vehicle. In reference to poor road network and other limitations, another health worker noted:

However these mobile services are usually hampered due to lack of financial resources for fuel and manpower. With such constraints, it is usually difficult to say or plan the number of visits we are going to do per month, it is not frequent, so we only do it as and when the resources are there. Then we have the poor road network, in some places, roads do not exist, we have a 4 × 4 but we can't still reach certain places.

As part of community services, the facility also provided sensitization on HIV and AIDS. Being run by the Roman Catholic Church, the facility did not distribute condoms. However, community sensitization activities were hampered by the same limitations affecting mobile VCT, of inadequate staffing, poor road network and inadequate funding.

For follow ups, the facility depended on community treatment supporters. The study discovered that the mechanism had a lot of challenges particularly, for remote communities due to lack of transport. However, there was optimism among staff that the mechanism would improve as the facility was in the process of acquiring bicycles for treatment supporters covering hard-to-reach areas. The poor follow up mechanism was also attributed to what one care provider referred to as, "Allowance syndrome" making some health staff and community health workers not being interested in any extra work without an allowance.

3.2. VCT and ART Physical Infrastructure

The building at the hospital which housed ART clinic was specifically built for that purpose. However, the space was clearly inadequate, leading to congestion. The building had three rooms consisting of a waiting room, registry, a consultation room

and a tiny corridor with a sitting capacity of about ten people. The waiting room, which was also the group counselling room, could only accommodate about twenty people at a time. According to health care providers this made group counselling, which was supposed to be conducted on each ART day difficult. Yet clients saw group counselling sessions as very important for adherence. The study discovered that, though very critical, special private counselling rooms were not available. The screening and dispensing of drugs were done in the same room while the registry was also the counselling room. Clients waiting to see the clinical officer and those collecting files waited in the small corridor which was very close to the counselling room. It was observed that due to the corridor being too small, some clients sat right in front of the room where counselling was taking place. This required both the counsellor and the client to speak in low tones knowing that there were people sitting right in front of the room. The data/health communication room was also lacking.

These inadequacies in terms of infrastructure had implications on quality of services provide by the facility. For instance, inadequate space had negative implications on the quality of counselling and other services offered. This is clear from the concerns raised by both key informants and community members who viewed it as compromising privacy and confidentiality required for counselling. These concerns can be illustrated by the following quotes:

We also need a bigger building so as to accommodate all these services that we are providing. For counselling we need privacy so that patients can be free and comfortable. At the moment this is lacking and as a result clients are limited as to how much they can share with the counsellor because instead of having only 2 people in a room there are usually more than two people in the same room because registry is also the counselling room. So even when they happen to have questions about their treatment and condition, some may not say anything (Male health care provider). The rooms are not enough, you find in the room there are many of you, maybe more than three yet you are supposed to be only two of you with the counsellor, there is no privacy at all. Most of the time as you are talking to the counsellor there is another nurse giving out cards and people keep coming in and going out of the same room and you get distracted.(male ARV user, male clinic based FGD amid agreement and support from other discussants).

Observations and discussions with health care providers revealed that clients' records were kept on open shelves yet the WHO guidelines recommend that such records should be kept in lockable storage for confidentiality purposes.

3.3. VCT and ART Staff

The staff from the main facility worked at the ART clinic on rotational basis. Among the reasons given for this were the inadequate staffing and need for all staff to have experience in providing ART services. Another reason given was to enable all staff working at the facility to have a share in the allowances which were provided by CHAZ for the ART clinic. Inadequate staffing was also cited as partly the reason why the clinic was held only twice in a week.

Consultations with health providers revealed that, on each ART day, there were supposed to be a clinical officer, registered nurse, a pharmacist, a nurse for bleeding, three four counsellors for adherence and an information officer. However, this was not

always the case. For instance, at times only one to two staff were found at the facility to conduct all the procedures. Additionally, the facility was supposed to have two clinical officers (COs) but only had one to attend to the Out Patient Department (OPD), In-Patient Department (IPD) and ART clinic. As a result, the clinical officer had to first do the rounds in the wards and attend to any emergencies at the OPD before going to the ART clinic.

Generally, most of the members of staff at the facility complained of being over-worked since the introduction of VCT and ART services. It was pointed out that the new services were being offered in addition to the other duties yet the number of members staff remained exactly the same. This was a great constraint and affected service delivery to people intending to access HIV and AIDS related services in many ways. Firstly, it was observed that because of inadequate staffing, people waited for a long time before being attended to. The fact that the whole facility only had one clinical officer and he was required to start with general health service delivery and was only able to go to the ART clinic after 10:00 hours yet some clients came as early as 5:00 hrs. Secondly, it was discovered that counselling sessions were much shorter than they were supposed to be. For instance, one of the health care providers informed the researcher that these counselling sessions were supposed to last not less than 20 minutes but because the counsellors were not enough, counselling time was much shorter. These deficiencies imply that the quality of services delivered was greatly compromised. Views from one of the health care providers are illustrative of this situation when she narrated that:

The ART clinic was introduced without any changes in the number of staff. This has led to increased work load for the few staff available. For instance, the full establishment for the health facility even without the ART clinic is two clinical officers but we only have one. So on each ART day, the only clinical officer has to first do the rounds in the wards and attend to any emergencies at the OPD before going to the ART clinic. Not having enough staff is also partly the reason why the ART clinic is limited to only two days in a week.

Similar sentiments were expressed by several community members as illustrated by the following remarks:

The attitude of most health care providers is just okay but the problem is that the doctor (referring to the clinical officer) is just alone and patients are just too many and no one to help. Some people can wake up around 4:00 hours and they are here by 600 hrs. and they would be number 3 or so but the doctor only comes around 900 hrs. The doctor has to work at OPD and wards and after she has finished, that is when she attends to patients at ART. Even if you were the first one to arrive, you will go home around 13:00 hours. The workload is just too heavy for one person, if the government could at least send one or two more doctors so that they can assist each other (ART user a mid agreement and support from other discussants, female community based FGD).

According to the health care providers interviewed, their delivery of other services such as counseling was equally affected. These concerns can be elucidated by the view of one of the male health care providers when he stated that:

Even counseling if it has to be adequately done we need more counsellors considering the numbers of patients that we deal with. We are supposed to be with one patient for at least not less than 20 minutes but because sometimes there would be a lot of people to be seen and just a few of you to attend to them, this becomes very difficult. And also because many of them cover long distances to reach the clinic, you try to squeeze in as many as possible to ensure that all are attended to and by the end of the day you are completely exhausted. This also affects the way some health staff behave towards patients because they are human beings and they get tired.

3.4. Training in HIV and AIDS-Related Services

Only the clinical officer (CO) and the ART Coordinator were found to have official training in ART services. These services consisted of adult ART management, pediatrics and VCT diagnostic and counselling. It was revealed that nine health care providers were trained in counselling with only one nurse having been oriented to carry out all the requirements for dispensing of ART yet they were all expected to carry out HIV and AIDS-related services.

The training was provided by CHAZ. However, the study discovered that even when a nurse had been fully oriented in all the areas of ART services, she or he could not initiate treatment because this was not allowed by the national guidelines if neither the clinical officer nor doctor were around.

All the community cadres who included peer educators, HIV medics, treatment and adherence supporters, were found to have only done some basic orientation to ART services for a week. In the actual fact, nearly all the community cadres complained of the training received not being adequate. Most of them stated that the training they covered in one week should have been done in three months implying that most of the training material was left out. Thus, expressing concerns about training needs, a male lay counselor remarked:

We definitely need further training in ART delivery because so far we have just been oriented for one week, under normal circumstances, the course we did should have been done in two months but it was compressed and so we covered it in one week. Though we were trained in both counselling and palliative care, this is still not enough. We need more training in all areas of ART.

In a related interview, a female health care provider also noted:

All members of staff need more training so that they can be competent in ART delivery, at the moment only the CO and the ART coordinator have had official training in ART services, the rest of the staff have only undergone orientation for one week and this is not enough to enable them adequately handle all the issues that relate to provision of ART services.

It was also revealed that at times health care providers who were adequately trained in ART delivery were not always working at the ART clinic as staff worked at the clinic on rotational basis. In essence, this compounded the inadequate training of staff in ART delivery. Gaining experience from working in the ART clinic would have been a cushion for inadequate training. For instance, it was found that the only nurse who had been oriented in all the areas of ART delivery and once coordinator for the ART clinic was at the time of the study, no longer working at the ART clinic but at the OPD. This did not only disrupt continuity in experience but was also a clear

misplacement of training and experience yet both were very essential for a specialized field like ART delivery. According to some of the users, this was viewed as compromising confidentiality, which can also be a limiting factor to those people who want to access and utilize available services.

3.5. VCT and ART Equipment

In terms of laboratory management the only equipment that the facility had was as sputum smear microscope for latent TB diagnosis. Reagents were also always available through the involvement of both the government and CHAZ in the distribution of these items. At times Total Control of the Epidemic (TCE), a cooperating partner in VCT, also provided testing reagents. This made basic testing such as rapid testing always possible. However, major equipment such as CD4 count machine for viral load monitoring, sputum test machine, hematology and, hemoglobin machines, full serum chemistry analyzer and antibody test machines were all lacking.

Samples for liver and kidney functioning were being sent to the District Hospital because the facility lacked a chemistry analyzer and CD4 count machine. This was done two times a month. There was much concern by health care providers over the lack of these basic but essential testing machines because this required that all samples delivered to Mazabuka District Hospital located more than 60 km away. This was a big challenge particularly during the rainy season as the road connecting the two health facilities was at times impassable. At times the health facility also experienced logistical problems. All this meant re-taking blood samples, a situation that sometimes raised suspicions and resistance from some of the members of the community who suspected some health care providers of being involved in Satanism, thereby using their blood for rituals. This resulted into reluctance on the part of some potential users and dissuaded some of those believing such allegations from HIV testing, and consequently limiting the access to ART.

Lack of testing equipment was reported to lead to delays in getting test results and consequently caused delays in linking positive clients to care and initiating treatment for eligible clients as a confirmed HIV test result was required before treatment could be initiated. Many study participants from both the health facility and the community narrated how lack of equipment delayed people to get their test results, be linked to care and be initiated on ART. Some of these experiences are expressed in the quotes below:

The frequency of transporting blood samples increases depending on the number of people queuing up for testing in a particular month. The problem is that sometimes the machine breaks down on the day the samples are taken due to too much pressure because we are not the only health facility that takes samples there. When this happens, blood samples have to be retaken because we cannot keep them beyond 24 hrs. before testing. This leads to delay in initiating patients on medication because there is a requirement that results are known before a client can be put on drugs (Male health care provide). Some testing machines should be acquired because that is one thing that delays people to start medication, some die while waiting for test results because our blood has to be taken to Mazabuka and then sometimes we are told that there was need for fresh blood and tests to be repeated meanwhile the patient keeps waiting for results without any medication even when one could be very ill (middle

aged female ARV user, clinic based FGD). If only the samples could be tested here [at Chivuna health facility] it would have been better but now patients have to wait for samples to be taken to Mazabuka and then results to come before somebody can be given the drugs, this causes a lot of delay, some of our colleagues have died in the process of waiting (male on ART for 3 years, clinic based IDI).

To some extent the delays and the re-taking of blood samples lead to mistrust and suspicions of some health care providers. It was also suspected that repeated taking of blood samples was to enable some health care providers use the collected blood for satanic rituals. Further, it was revealed that some eligible clients were in the process of waiting for test results lost. One ART client stated that:

That happens a lot [referring to retaking of blood samples], like for me, they had collected blood more than two times from me. Because of drawing blood from you on a daily basis in the end, they can even drain the last of drop of blood from you, sometimes you start thinking of possibility of other things happening, we do not know what happens maybe our blood is being sold (Female ARV user, mixed clinic based FGD, amid agreement from other participants).

Such concerns were confirmed by some health care providers as one of them stated that:

Yes there is some talking about that [repeated blood taking]. Some clients have even approached me jokingly asking about where we take their blood and whether we sell it. They have heard about Satanism yes and so they ask such questions. This is made worse by the re-taking of blood samples we have talked about. And then results do delay sometimes because of not having our own machines here. Before our CD4 count machine was taken to Chikankata Hospital things were much better. We have lost some patients in this manner (male health care provider.)

Some health staff expressed how frustrated they felt at times when they were unable to initiate treatment due to delayed test results even when some clients would be showing signs of deteriorating health status. It was further reported that in the beginning, a CD4 count machine was allocated to the facility by CHAZ. This equipment had since been transferred to another much bigger health facility located about more than 50 kilometres away. In addition to this, the facility also lacked many other equipment required as minimum standard for a facility offering HIV and AIDS-related services.

3.6. Supply of HIV and AIDS Drugs

All the drugs required for the administration of ART were provided by both CHAZ and government through medical stores. The facility had never experienced any drug shortages and had in stock both first line and second line ARVs. The readily and consistent availability of ARV drugs was an important predictor for drug compliance, an assertion verified by all sources, including physical checks on all ART days. The readily availability of ARVs encouraged people to cover the long distances to the health facility and was hence a facilitator for adherence. Antibiotics for prophylaxis were also always available. This finding was unique to the study area because at the time of the study there were protests in other parts of the country due to shortages of HIV and AIDS-related drugs, particularly ARVs. There was Post-Exposure Prophylaxes (PEP)

only for members of staff. However, at the time of the study incidences requiring these services such as accidental needle pricking of staff had never occurred at the facility.

**4. Discussion**

The study sought out to assess quality assurance in HIV/AIDs-related services in Chivuna Health facility and generally, the findings indicate that HIV/AIDS services were available at the facility. However, as observed before by other qualitative studies in the region [7] [8] , the present study identified a number of gaps when compared with the WHO minimum standard guidelines in provision of VCT and ART services. The results from our study do confirm that these inadequacies affected the effective operations of the facility. The gaps did exist in nearly all the key departments of VCT and ART delivery. In laboratory management for example, the CD4 count, the hematology machine and chemistry analyzer were lacking. As observed by [8] , this inevitably contributes to delays in people getting their results and consequently delays in those found HIV positive in accessing the care and treatment they require. Inadequate laboratory equipment also affected ART monitoring. This has also been observed by other authors [5] [6] .

Physical infrastructure was also observed to be below the WHO standards. Instead of having at least six rooms for counselling, screening, record keeping, counselling, waiting room, dispensing and data room as per minimum requirements, our results reveal that Chivuna health facility only had three rooms. This led to combining of some of the services in a single room. This also meant that some of the services provided were not as effective as they are expected to be. For instance, because of lack of specific counselling rooms, the quality of counselling was compromised due to confidentiality concerns. The situation also has potential to prevent clients from seeing seeking counselling at the facility.

Study findings also reveal, a finding not unique to this study but common in many earlier studies also [10] [11] [12] [13] the facility experienced staff shortages. Our findings show that staff shortages impacted negatively on counselling, waiting and opening times. For instance, because of low staffing levels, our findings show that the length of counseling sessions was reduced. In the same vein, because of inadequate staffing, particularly in relation to the fact that there was only one clinical officer to carry out all the services at the facility, people were subjected to longer waiting times. And as earlier reported [14] [15] [16] , inadequate staffing leads to burn out among health care providers because they end up being over worked, a situation that compromise the quality of care delivered. In Chivuna, shortage of staff was also the reason given for providing ART only three times in a week.

Training in HIV and AIDS-related services was also inadequate. The lack of training in a way contributed to the lack of confidentiality among some of the health staff, which equally emerged as a barrier to people entering and being retained in the HIV continuum of care. Like inadequate staffing alluded to above, inadequate training in ART delivery negatively impact on the quality provided. In all their studies from Botswana, Uganda and Tanzania, [15] , cite the importance of having well trained health care staff in ensuring provision of quality HIV and AIDS-related counselling as a way of enhancing access to HIV and AIDS-related services.

Lack of trained staff in ART is both a risk to staff and clients and may compound the problems. When clients become aware that staff are not adequately trained, they may lose confidence in the facility and possibly resort to other means such as traditional medicines which are largely neither scientifically tested nor approved. Lack of training among ART staff and its negative effects has been reported also by other qualitative studies from other countries within the region [9] [14] [17] and from Zambia [18] [19] [20] . In our study area, lack of training was compounded by lack of continuity in service delivery by health staff in that they worked at the ART clinic on a rotational basis.

Generally, as observed above all these gaps had negative implications on the effectiveness of the services delivered. Earlier studies within the region [8] [10] [17] [21] all observe inadequacies in many health institution accredited to provide HIV- and AIDS-related services. The inadequacies in the health delivery system identified above affected the effectiveness in the delivery of HIV and AIDS-related services.

It should be mentioned nonetheless, that the fact that Chivuna health facility never run out of ARV drugs, both first line and second line drugs, was an important predictor for drug compliance because it encouraged people living with HIV to cover inconceivably long distances to the health facility knowing that they will find them each time they went there. As stipulated by the WHO guidelines, uninterrupted provision of ARVs was critical so as to avoid treatment interruptions if drug resistance is to be prevented and also make ART effective. This was an interesting finding considering that a number of previous studies have reported of drug shortages or irregular medical supplies due to weak procurement procedures as being critical barrier to ART access and adherence [8] [14] [19] [22] [23] . Additionally, Chivuna health facility had sputum machine and always had reagents for various tests.

## 5. Conclusion

The findings from this study have shown that while HIV/AIDs-related services were available in rural settings like Chivuna, a number of gaps were recorded. The findings indicate that a few services, such as uninterrupted supply of ARVs and availability of reagents were in line with WHO guidelines. However, for the majority of the services were below the WHO minimum standard guidelines for the provision of such services. These inadequacies in the health delivery system contributed to poor service delivery. Therefore, for HIV and AIDS-related services to be effective and also ensure universal access to these lifesaving services, there is need for government and cooperating partners to address these inadequacies so as to optimize access to care for people living with HIV. This is important because provision of health care in itself is not enough with assuring the quality of care provided and hence the need to address it.

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# M.F.Akhundov in M.B.Mahammadzada's literary heritage of emigration period

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**Abstract** *Mirza Bala Mahammadzada (1898, Baku- 1959, Istanbul) is one of the prominent personalities having exceptional contributions in social-political, literary- cultural and scientific thought history. As he was a political emigrant in Turkey during Soviet period his life, multi- branched activity and rich creativity were remained out of sight of the researchers, no work was carried out in the sphere of publication and agitation of his scientific and literary heritage. However, both in the period of emigration and living in motherland until the 20s years of the XX century B.M.Mahammadzada worked very effectively and made a plenty of publisistic writings related with the most topical problems of the society. Until emigration he had laid foundation of research of the history of national media with his "Between two revolutions" (1918, Tbilisi) and "Azerbaijan Turkish media" (1922, Baku) monographs*.

**Keywords:** *Mirza Bala Mammadzadah, Azerbaijan Turkish poetry, literature*

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Researches on classic literature of Azerbaijan have a special place among M.B.Mahammadzada's scientific works which he wrote during his emigration years in Turkey. It should be noted that M.B.Mahammadzada's literary heritage of scientific works in emigration period involving researches on M.F.Akhundzada (1812-1878) who laid foundation of professional drama genre, realist artistic prose and literary criticism in Azerbaijan literature, besides being a great contribution to our country's literary study, also

played a significant role in study of his work in Turkey and keep on providing modern Turkish researchers with abundant materials.

We will conduct analyses on M.B.Mahammadzada's three work included to his scientific heritage of emigration period. These are the articles - "Fatali Akhundzada" (1), Mirza Fatali and alphabet revolution" (2) and Mirza Fatali and Pushkin" (3). The article "Fatali Akhundzada" was published in 1945, in Islam Encyclopedia, the other two were published in "Azerbaijan" journal printed in Ankara, Turkey. It also should be noted that in all three articles we come across factual erroneousness and it is related with objective reasons; in emigration M.B.Mahammadzada did not have sufficient literature with him, moreover during the years when the articles were written even in Azerbaijan the science of studying Akhundov was in the stage of formation. It also should be emphasized that in the articles there are also M.B.Mahammadzada's own thoughts and considerations born from his political views. And in many cases it reaches to an extreme degree. Presentation of analyses born from purely subjective approach as an absolute truth is regrettable and it does not fit with M.B.Mahammadzada's known level of scientific thinking. M.B.Mahammadzada in the introduction of his article "Fatali Akhundzada" evaluated the role of M.F.Akhundzada in the history of morality of the nation he belonged to quite right and presented him to the Turkish readers as "The first playwright and story-writer who laid foundation of new Azerbaijan literature with his comedies written in Turkish, the first westernist and critic, a herald of alphabet revolution in Turkish with his ideas and initiations on change of Arabian alphabet (1, 577). In the article first period of M.F.Akhundzada's life, his undergoing a family drama due to his parents' divorce, his "second father" Akhund Haji Alasgar's patronage on him, childhood years spent in the Southern Azerbaijan villages, Akhund Haji Alasgar's intention to raise him as a theologian, etc. were given. M.B.Mahammadzada paying special attention to M.F.Akhundzada's first education issue, considered his entering to Russian school and his learning Russian language a planned proposition. He thinks that there is a "secret" relation between Fatali's effort to learn Russian and his once and for ever abandoning the way of priesthood. M.B.Mahammadzada wrote: "The point which requires an attention is pursuit of a second incident his initiation to learn Russian..." (1,578). When he said the "second incident" he meant Fatali's courageous step to go to Tbilisi which changed his future way of life completely: "Haji Alasgar's intention to raise Fatali as a religious scholar as himself remained ineffective due to, as Fatali writes in his biography, "an issue which happened unexpectedly" (1, 578). Actually, M.B.Mahammadzada could not specify what M.F.Akhundov meant (the popular talk between Mirza Shafi Vazeh and young Fatali-Sh.M.) when he said "an issue taking place unexpectedly", but in any way he demonstrated a scientific approach to the problem by saying that behind change of his initial world outlook stood quite serious reasons and by substantiating his thoughts in his own way. M.B.Mahammadzada connected it with the social-political- historical situation formed in Northern Azerbaijan after Turkmanchay contract (1828) concluded between Iran and Russia. According to M.B.Mahammadzada, restoration of Russian influence in the region and irreversibility of political events shocked the local ruling class and "made them to go to compromise to the Russians" and in a short period there was formed "an intellectual class consisting of the generation trying to assimilate Eastern and Western cultures and serving the Russian in compliance with new conditions" (1, 578). M.B.Mahammadzada reminded M.Sh.Vazeh, A.Bakikhanov, Mirza Kazim bey and M.J.Topchubashov as the first representatives of this class. With this he denied the reason "philosophy" born from atheism,

the ideological branch of the political system put forward by the Soviet Akhundov studiers claiming that "Fatali abandoned the field of theology and left for Tbilisi for public administration work due to Mirza Shafi's reproach ("Do you really want to be hypocrite and charlatan?... Do not waste your life among these disgusting people! Go for another specialty"). We think that the reason, or to be more exact, the change in his initial world outlook that guided Fatali to Tbilisi was directly related with social- political processes of the period and in this issue, we fully agree with M.B.Mahammadzada's considerations. In the article the attention was also paid to M.F.Akhundzada's successes in literary creativity who was working as a translator in the Caucasus viceroyalty. M.B.Mahammadzada referring to the autobiography written by M.F.Akhundov indicated that behind this success there stood political objections:

"His works were published still at that time under the name "Tamsilat" and were represented in Tbilisi palace. This favor of Russian mayor to Turkish language was related with a number of political reasons designed for eliminating the influence of the Persian culture on Azerbaijan and to replace it with Russian impact and it is understood from the documents published later showing Russian colonialism policy in Azerbaijan". (1, 578). It should be noted that this issue was firstly touched in the work "Caucasus Turks" which was written in 1928 by M.A.Rasulzada, one of the founders of the first democratic republic in the East- Democratic Republic of Azerbaijan (4). M.A.Rasulzada wrote about above-mentioned aim of Russia 17 years before M.B.Mahammadzada: "…Russia agitated to write in national Azerbaijan Turkish in order to oppose the East against Iran influence in the Caucasian. Mirza Fatali who is considered the founder of modern Azerbaijan literature wrote his popular comedies with agitation of Vorontsov, the governor-general of Caucasus viceroyalty and as the first Turkish comedies were staged in Tbilisi palace, the writer's works were also published in the publishing house of the governor-general" (4, 29 ). Of course, governor-general of the Caucasus viceroyalty M.S.Vorontsov's "favors" for M.F.Akhundzada had evident purposes behind; if on one hand with establishment of national –cultural institutions in the Caucasus the writers were agitated, on another hand the main aim was to put away the tradition of writing in Persian. Although these issues were conducted on a political background and were calculated for political objections, it was a favor of the history that finally it turned into a service to a national literature and culture. In this sense, although M.F.Akhundzada and Georgian playwright G.Eristavi seem skillful players of this policy, their creativity served for enrichment of the national literature with new types and genres. From this point of view, M.B.Mahammadzada's conclusion on this issue is quite right: "Fatali managed to establish a new literary school opening a new period both in national thinking, and national art fields" (1, 578-579). The analyses show that the aim of the Russian czarism was not only to eliminate Persian influence. Planned rusification policy was being carried out on the background of the care for the national culture. That is, the Persian influence was planned to be replaced by the Russian influence at the end. Establishment of Russian theatre in 1854 in Tbilisi served to implementation of this goal intending spread of Russian language and culture among the local people. The governor-general M.S.Vorontsov wrote it openly in his letter to Gedenov, the director of the Russian Imperial Theatre, asking him to send a theatre troupe for a tour to Tbilisi (5, 9). In the letter that the governor-general of the Caucasus viceroyalty sent to his friend Shepkin on the same day asked him to send an appropriate troupe from Moscow and explained its significance (5, 10). The researcher Ali Musayev while talking about establishment of the Russian theatre in Tbilisi draws attention

to M.S.Vorontsov's letter he sent to Nicolay I in 1850. In the letter it is noted that the main aim is provision of assimilation of the local people with the Russians… (6, 12). M.B.Mahhamadzada in his researches gave a wide place to M.F.Akhundzada's insistent struggle for new alphabet project and its implementation. In the article written for Islam Encyclopedia M.F.Akhundzada's activity in this sphere had been followed, it was indicated that being impressed by ineffectiveness and failure of his appeals to Istanbul and Teheran he wrote a number of literary works. It should be noted that M.B.Mahammadzada spoke comprehensively about M.F.Akhundzada's struggle for alphabet in his article "Mirza Fatali Akhundzada and his alphabet revolution" (2). In this article based on deep scientific content some considerations causing dispute are also met. After the analyses M.B.Mahammadzada concludes such a verdict that behind M.F.Akhundzada's alphabet projects there stood his intention to make it adopted by Ottoman state or Iran, not to the Russian government to which he served" and it was related with his uncompromising attitude to Russia.

Generally, M.B.Mahammadzada in all three articles of his wrote that M.F.Akhundzada had a hostile attitude towards Russia and "rusification". According to him, M.F.Akhundzada although lost his belief in Turkey and Iran, continued his struggle until the end, however "did not even thought about implementation of this project via Russian channel". Mirza Fatali, describing the Russian king Nicolay I as "a bandit of the world-wide scale" and desiring to raise the contemporary culture of the Moslem nations could not act otherwise" (2, 4). In fact, in these considerations putting aside the essence of M.F.Akhundzada's choice in favor of Turkey and Iran, he tried to politicize the problem and to show allegedly opposite position of the reformist thinker against Russia. Not going further into details let's in briefly note that M.F.Akhundzada sent his alphabet project to Turkey, Iran, as well as Europe's five main countries and scientific circles in 1857 namely via Russian official channels. From M.F.Akhundov's epistolary heritage it seems that his activities related with a new alphabet had been in the focus of the official circles in Tbilisi up to its smallest details and he agreed every step of his with them. The reasons of launch of Turkish and Persian "channels" in alphabet issue were more accurately evaluated by an emigrant researcher Abdulvahab Yurdsever: "The enlightener earlier proposed this project to Ottoman government. Because Ottoman Empire had an exceptional religious and spiritual influence on all Islam world. This activity, at the same time, shows Mirza Fatali's deep commitment to Turkish and Islamic world. He avoided any individual action. If there was any need for reformation or complete change of the alphabet, according to him, it would be carried out at least with Turkey and Iran. It could not be performed alone. Azerbaijan's cultural relations with Turkey and Iran could not be tear out" (7, p.21). M.B.Mahammadzada's wrong position in this issue, his quite emotional attitude to this problem seems also to be related with two-headed policy of soviet regime regarding alphabet.

Only 10 years later after official replacement of Arabian graphics alphabet with Latin graphics in Azerbaijan in 1929, a transition to Cyrillic alphabet in 1939 M.B.Mahammadzada evaluated as a betrayal to M.F.Akhundzada's ideal, and considered it integral part of a planned policy: "Latin alphabet was removed and Russian alphabet was put into use in order to break the cultural unity ties with the Turks" (2, 5).

M.F.Akhundzada's calling Nicolay I "a bandit on a world scale" is far from the truth. In the original version of the writer's ode known under the name of "Eastern ode to A.S.Pushkin's death" and in the text published in "Moscow observer" for the first time such a phrase was not used: "But why did M.B.Mahammadzada declar such an accusation from

the name of M.F.Akhundzada? In order to bring clarification to this or other questions, it is important to pay attention to the original version of the work in Persian (8), the first printed variant (9, 297-302; 10, 145-151) and the second printed variant (11, 76-79).

It should be noted that M.F.Akhundzada wrote this work in Perisan and gave no name to it: "It is a mourning ode written by 25-year old Mirza Fatali Akhundzada to the death of the prominent Russian poet Pushkin" is not the name of the work, it is just dedication words of the author to the ode". M.F.Akhundzada himself translated this ode into Russian and adding 12 explanations to it, presented to I.I.Klementyev serving in Tbilisi. I.I.Klementyev sent the ode together with his letter to the editor of the journal S.P.Sheviryov. The editorship of the journal published this "beautiful flower put on Pushkin's grave" without any change in 1837, March issue. In the work czar Nicolay's name was reminded only in one place, and exceptionally in a positive meaning.

In original in Persian:

"Gereit şöhrəte fəzləş cehan be don gune

Ke şöhrəte Nikolay əz xətay ta tatar" (8)

In "Moscow observer":

"Распространилась слава его гения по Европе, как могущество и величие Николая от Китая до Татарии" (10, 149). ("The glory of his genius spread across Europe like the power and greatness of Nicholay from China to Tataria)

For the second time, the ode was published in 1874, in the 11th issue of the journal "Russian antiquities" with a brief introduction of Adolf Berje (11, 76-79). In the journal the ode for the first time was called namely a poem: "Eastern poem to Pushkin's death". It is known from Berja's notes that a bit later from publication of the ode in "Moscow observer" journal baron Rozen asked Russian writer A.A.Bestujov-Marlinski who was in a military expedition (M.F.Akhundzada was also participant of this expedition) in Abkhazia, Sebel region with him to translate the poem into Russian together with the author. A.A.Bestujev – Marlinski carried out this request of his in a short time. It was the last work of the Russian writer, a bit later, he was killed in a fight against the mountaineers. It is evident that M.F.Akhundov himself told this short introduction to A.Berje and it should be noted that the copy of the ode was given to him by the author also. Here, it also becomes clear that namely A.Berje called this ode a poem.

Comparison of the first published text and the text on which A.A.Bestujev-Marlinski worked shows that the Russian writer did not translate the ode completely once again. He conducted only small editorship works (8; 9, 297-302; 10, 145-151; 11, 76-79). In the line which we take from the "Moscow observer" the words "...and Nicolay's greatness" were extracted and the line was given in "Russian antiquities"' in such a form:

"Разошлась слава его по Европе, как могущество царское…" (11, 78). ("His glory spread throughout Europe as the royal power")

Later in the text we come across the parts differing from the original which led M.B.Mahamaadzada's incorrect thought. Let's pay attention to differences of one of these parts: In M.F.Akhundzada's translation into Russian ("Moscow observer"): "Russia claims about it with sorrow: "О убитый рукою убийцы-злодея" ("Hey, you killed by a killer-villain") (9, 302; 10, 151). In A.A.Bestujev-Marlinski's editorship ("Russian antiquities"): "Россия в скорби и воздыхании восклицает по нем: "Убитый зладейской рукою разбойника мира" (11, 79). ("Russia is in grief and sighs on him: "He was killed by the evil hand of the killer"). By the way, it should be noted that the ode had been translated from

Persian into Azerbaijani by M.Mushfig, B.Gasimzada and J.Khandan and in none of the translations the phrase "the bandit of the world" was used. Let's pay attention to two of these translations:

"Rusiya dad-fəğan ilə sual etdi yenə:
"Nə üçün quldur əlindən bu təbiət də sənə
Bir xilaskar ana qəlbilə aman vermədi, ah!" (12, 232).
Or:
"Rus torpağı yas tutub, fəğan qılır ki,
Ey qatillər əlilə ölən namidar" (13, 158).

Unlike the original in Persian in translations into Azerbaijan in spite of "Nicolay" the word "czar" was used. The ode was included to "Selected works" by A.A.Bestuyev-Marlinksi published in 1990 in Russian language as his translation in the version and with the name as it was issued in 'Russian antiques" (14, 224-227). As it seems, M.F.Akhundzada in fact, did not call czar Nicolay I "a bandit in a world scale". As A.A.Bestuyev-Marlinksi's editorship in a known style in "Russian antiquities" fitted the soviet ideology, the fibs about M.F.Akhundzada's opposite position against the czar sometimes penetrated to scientific literature also.

Therefore, it is evident from where erroneous considerations of M.B.Mahammadzada who was in an enemy position against the Russian czarist regime in the example of the czarist Russia and Soviet government, derived. M.B.Mahammadzada in his article "Mirza Fatali and Pushkin" (3) stated quite contradictive thoughts regarding the leitmotif of M.F.Akhundzada's above-mentioned ode, as well as the sources from which he benefited in writing it. According to his writing, when M.F.Akhundzada began to his activity as a playwright since 1850 as if he managed to learn French, "but at the time when he dedicated an ode to Pushkin's death, he knew none of western languages" (3, 6). Firstly, M.F.Akhundzada, did not know any of Western languages, including French. It can be seen from his letter to a French diplomat Monsieur Nicolay in December, 6, 1872: "I do not know any European language except Russian" (15, 215). Secondly, why M.F.Akhundzada had to know one of the Western languages in order to write an ode about Russian poet? From M.B.Mahammadzada's conclusions it follows that the author in his ode "… allotted a wider place to Western literature and culture which raised Russian writers including Pushkin" (3, 6) and due to this reason, as he did not know any of western languages he got the necessary information via Ottoman Turkish or by searching. We suppose, it does not need any further explanation. In brief, it should be noted that in the ode there is no talk about Western literature and culture, and M.F.Akhundzada would not need any search for information. Regarding to the influence of European literature on A.S.Pushkin, it is quite a different problem and M.F.Akhundzada in his ode had not got any objections on resolution of this problem. In the article an effort to analyze Pushkin's literary creativity on a political plane, putting aside his position in Russian literature draws attention. Moreover, it is difficult to put up with his verdict that after returning from the exile A.S.Pushkin became a palace poet. According to M.B.Mahammadzada, actually in the poem "Great Peter's Arab" Pushkin was charmed not with Peter's absolutism, but with his imperialism which he evaluated as "patriotism". Or in the poem "Poltava" claiming that Pushkin enjoyed Peter's "bloody freedom" approached to the issue from another prism. M.B.Mahammadzada trying to draw his "political portrait" in this or another sample of Russian poet's poems later came to an interesting conclusion: "Because of this, Mirza Fatali considering him (Pushkin –Sh.M.) the

enemy of czarism and brave freedom fighter devoted a poem to him, but later he reminded his name neither in his literary nor in philosophical works" (3, 8). From M.B.Mahammadzada's logic it follows that A.S.Pushkin's attitude to czarism did not satisfy M.B.Akhundzada. At that time, we need to speak about political identity of M.F.Akhundzada. Actually, at the end of the article, he determined M.F.Akhundzada's political identity in his own way. It will be talked further.

In the article there is a serious objection against soviet political ideology presenting M.F.Akhundzada as "a supporter of Russian culture". Rejecting this thought M.B.Mahammadzada wrote that in neither of his works including his ode dedicated to Pushkin M.F.Akhundov reminded "Russian literature", "Russian culture" and showed "no admiration for Russians" (3, 8). Of course, political system used the personality of M.F.Akhundzada abundantly for conjecture purposes. In Soviet period the social-scientific movement founded by M.F.Akhundzada rejecting Arabian graphic alphabet was very often offended, and with transition to Cyrillic alphabet an ugly policy was conducted to break out the moral relation of Turkish nations in the USSR with Turkey. M.F.Akhundzada's conceptual thoughts about modernization of the society, integration of his nation to the cultural world were skillfully interpreted. For Soviet political system M.F.Akhundzada was quite good history to be acquired. Not modern, namely historical past! Emigrant researcher Abdulvahab Yurdsever paying attention to this point wrote: "This point is exact that if Mirza Fatali lived in Soviet period, he would be either shot or expelled to Siberia as the well-known Azerbaijan researcher Firudin Kocharli, poet Huseyn Javid, Ahmad Javad and other numerous great writers, intellectuals, artists and scholars" (7, 25).

However, only one poem dedicated to Pushkin is not enough for speaking about M.F.Akhundzada on the plain explaining whether he was admirer of the Russia. In M.F.Akhundzada's literary and philosophical works, in his rich epistolary heritage integration to Europe was put forward as a serious issue. With his social-political views, thoughts on society M.F.Akhundzada were close to Western philosophers and writers. He had deep knowledge on creativity of Volter, Montesquieu, Russo, Duma, Fenelon, Bokl, Shakespeare, Volney and others the names of whom he reminded in his works not once. In his outlook A.S.Pushkin was the founder of new-period Russian literature, a great poet gained love of the nation and he did not devote the ode to his death as "an admiration to Russia". Again we share A.Yurdsever's attitude in regard to this issue: "The writers as Pushkin and Lev Tolstoy are highly evaluated in the world culture. Everybody reads them in different languages and approves their literary genius. Our admiration for them is not because they are Russians or belong to Russian culture, but because they described the human life and soul masterfully leaving immortal works behind them." (7, 26).

M.B.Mahammadzada in his article reminded three plays by M.FAkhundzada and tried to clarify the aim of the author in them, however, could not demonstrate a right approach. In a word, in a concrete case he could not manage to clarify the problem of author's position. Perhaps, here also his own political view, his personal attitude to Russian governance, Russian law hindered him to find out the idea of the work correctly.

For example, according to him, M.F.Akhundzada in his work "Hekayeti-khirs guldurbasan" described Russian government as a patron of smuggling and robbery (3, 8). Actually, M.F.Akhundzada's aim was not to reveal Russian governance. The author wanted to educate his countrymen who were supporters of old traditions by showing them in funny situations and it is an issue arising from his enlightening aesthetics.

At the end of the work Divanbeyi's speech who forgives Tanriverdi fully fits with the goal of the author: "Hey, people, let it be a lesson for you! It is high time for you to believe that you are not a wild tribe. It is a shame for you to join such evil work. Stop being engaged in theft, slyness!" (12, 98). Divanbeyi's final words were not more than "a green light" for M.F.Akhundzada to pass the censorship: "Do you know how much does the Russian government favor you and from what troubles protects? (12. 98) Or in the article M.B.Mahammadzada's thought on M.F.Akhundzada's another comedy did not fit the situation in a concrete case: "Mirza Fatali in his play "Vaziri-khani-Sarab" showed that no matter how liberal is the king, he will never be a reformist" (3, 8). However, in that comedy no issues related with a liberal king, reformism and other of such kind were put forward. Although differences in topics in all comedies M.F.Akhundzada speaks as an enlightener. Prominent literary critic Y.Garayev is fully right from this point of view: "In all "Tamsilat" the main aesthetic idea and literary ideal, as well as the outlook carry educational characteristics" (16, 230). According to M.B.Mahammadzada, M.F.Akhundzada in his literary works revealed Russian governance because he had not put up with colonialist policy of Russia in the region and considered him an enemy. In fact, with this conclusion M.B.Mahammadzada put forward political identity of the writer: "Azerbaijani Turk Mirza Fatali who struggled against the servitude discipline which Russians tried to make Azerbaijan adopt had a hatred against Russian governance, the symbol of ignorance... Mirza Fatali was against Russian governance and Russian social-political order, he was calling for a rebel against this regime." (3, 8). To my opinion, here the issue of M.F.Akhundzada's attitude to political system was made a bit severer, and was given in a very acute form. At least, it is possible to have a dispute on the last sentence. M.F.Akhundzada in the biography which he had written himself openly stated that the Caucasian governor-generals always respected him: " Since that date (since 1834 – Sh.M.) I am working in the position of a translator of Eastern languages at the Caucasian viceroys. They have always showed their respect and favor for me. I live in a welfare. I have had a rank of colonel. I am especially satisfied with the decent general-field marshal, knyaz Vorontsov, who had been my employer before Baron Rozen..." (15, 268). If to recall M.F.Akhundzada's orders and medals awarded to him by the government, the issue will be even more clarified. So, the claims about M.F.Akhundzada's hostile position against Russian political regime have no ground. But it does not mean that M.F.Akhundzada was a supporter of the colonial regime under which his nation was. M.F.Akhundzada did his best for modernization of the nation he belonged to, for its achieving the culture and prosperity as the European nations prepared conceptual basis of integration to Europe.

So, we can note that in spite of certain contradictive and disputable points, M.B.Mahammadzada'a articles on M.F.Akhundov's life and creativity although written approximately seventy years ago, preserve their significance and scientific value. There is a serious necessity for publication of M.B.Mahammadzada's both these articles and his other works which he wrote during emigration in Azerbaijan.

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# Biological Profile of HIV-Positive Patients in Bangui, Central African Republic, in 2017

**Yawo Tufa Nyasenu**

**Abstract** *The biological profile of HIV-positive patients is essential for diagnosing treatment failure and the prognosis of infection. We determined the virological and immunological profiles and biological anomalies of HIV-positive people on antiretroviral therapy (ART) in Bangui, Central Afri-can Republic.* ***Methods:*** *We conducted an analytical, descriptive study be-tween 4 April and 30 September 2017 of all patients who had received ART for more than 12 months and who attended the Medical Analysis Laboratory of the Institut Pasteur in Bangui for a complete biological work-up, including viral load. A blood sample was taken for quantification of RNA HIV-1, CD4 lymphocytes and blood count in two tubes containing ethylenediamine te-traacetic acid, and another sample was taken in a dry tube for measurement of creatinine and transaminases.* ***Results:*** *The total population comprised 1748 patients, with a mean age of 38.7 years (±14.3; median, 41 years; range, 2 - 79 years); 33.3% of patients were between 40 and 49 years old. Females predo-minated (71.3%), for a sex ratio of 0.4. Immunological failure was observed in 20.2% of patients (CD4 < 200 cells/µL), and 44.5% of patients had a load of RNA HIV-1 ≥ 1000 copies/mL. The main haematological anomalies were anaemia (28.0%), leukopenia (26.7%), neutropenia (42.1%) and lymphopenia (27.2%). Blood creatinine was abnormal in 61.0% of patients, ALAT in 57.0% and ASAT in 66.9%.* ***Conclusion:*** *The abnormalities observed in this study concerned the haematopoietic system, the liver and the kidneys. As other or-gans and systems may be affected, periodic multidisciplinary biological and clinical follow-up is necessary for people living with HIV in order to improve their management*

**Keywords:** Anaemia, Biological, Abnormalities, HIV-1, Bangui

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## Introduction

HIV/AIDS remains a major public health problem throughout the world and particularly in sub-Saharan Africa. In 2017, UNAIDS estimated that 20.9 million people were receiving antiretroviral therapy (ART). In 2016, 6.1 million people in West and Central Africa were living with HIV, and 31,000 died of diseases associated with AIDS, whereas only 2.1 million people, 35% of those living with HIV in the region, had access to ART. Women account for 56% of people living with HIV in the region. In 2016, there were 370,000 new infections with HIV, representing a reduction of 9% since 2010, and the number of deaths from AIDS decreased by 21%. Among children in West and Central Africa, there were 60,000 new cases of HIV infection in 2016, representing a decrease of 33% since 2010 [1] .

Treatment with multi-ART has prolonged survival, decreased morbidity and improved the quality of life of people living with HIV [2] [3] [4] [5] . ART, like HIV, may, however, attack various body systems and cause abnormalities in the haematopoietic system and organs such as the kidneys, the liver, the heart and muscles [6] [7] [8] . The drugs in ART may thus have undesirable, dangerous effects on patients [9] [10] . Interactions between drugs given for opportunistic and other infections (tuberculosis, hepatitis B) can have dangerous consequences [11] [12] [13] . Kobangue et al. [7] reported that anaemia was the cause of death of 75.8% of children on ART who died at the Paediatric Complex in Bangui between 2008 and 2013.

In the Central African Republic, there has been a decade of sociopolitical instability, which has resulted in population displacement and difficult access to treatment. The present study addresses the biological characteristics of patients on ART who attended the Institut Pasteur in Bangui for a free, complete biological follow-up as part of a national effort to improve their management.

## 2. Patients, Material and Methods

### 2.1. Setting and Patients

A cross-sectional descriptive study was conducted between 4 April and 30 September 2017 at the Institut Pasteur in Bangui, a recognized centre for public health, in collaboration with the International Committee of the Red Cross and Red Crescent Societies. The institute has a medical analytical laboratory, which provides biomedical analyses for the population of the country. We included all patients with HIV/AIDS who had been on ART for at least 12 months for whom systematic biological follow-up had been conducted during the study period. The inclusion criteria were the presence of HIV-1 infection, ART for at least 1 year and a complete biological work-up, which comprised plasma viral load, CD4 lymphocyte count, blood creatinine and transaminases and blood count. We excluded from this study: HIV-infected patients who were on treatment for less than one year, patients with incomplete biological

status, and patients infected with HIV-2. In this study using clinical files and electronic registers, the patient's identity was not collected in the survey file to ensure ethical clearence.

2.2. Sampling

Blood samples were taken for quantification of RNA HIV-1 and for blood counts in two tubes containing ethylene diamine tetra-acetic acid (EDTA), and another was taken in a dry tube for measurement of blood creatinine and transaminases.

2.3. Biological Analyses

RNA-HIV was extracted with a Biocentric kit (12.08.02-170510) on a NorDiag Arrow (AO637R3) extractor. Biocentric kits (TR001-250IC) were used for RNA-HIV amplification by real-time PCRon an Applied Biosystems 7500 Fast System (4357362). The targeted region is on the long terminal repeats (LTRs), and the detection threshold was 300 copies/mL in a sample of 10 µL. The technique is specific for HIV-1 group M, subtypes A-H. Blood creatinine with automated Jaffe colorimetric method, aspartate and alanine transaminases (ASAT and ALAT) were measured on ABX Pentra 400 (RAB1251FR). Blood creatinine was considered normal at 6 - 13 mg/L and ASAT and ALAT at 11 - 66 UI/L and 15 - 46 UI/L, respectively. An ABX Pentra 60 (111P6010797) from HORIBA was used for blood cell counts. Cut off for anaemia was defined as haemoglobin levels lower than 11 g/dL in women and lower than 12 g/dL in men.

2.4. Statistical Analysis

The analysis was performed on all data from included patients (exhaustive sampling). Data were entered onto an Excel® sheet and analysed with Stata software. We recorded the sex and age of our study population, the viral load, presented as <1000 copies/mL (virological failure) and ≥1000 copies/mL (virological success), and CD4 cell counts, with immunological failure defined as <200 cells/mm3 and immunological success as ≥200 cells/mm3. The World Health Organization (WHO) guidelines recommend the use of viral load as the preferred method for monitoring treatment response over clinical and immunological approaches, and define virological and immunological failure respectively with a threshold of 1000 copies/mL and 200 cells/mm3 [14] [15] . Student's t test, the chi-squared test and calculation of odds ratios (ORs) with 95% confidence intervals (CIs) were used to compare viral loads and CD4 cell counts according to biological abnormalities. The threshold for significance was set at 5%.

## 3. Results

A total of 1748 patients were entered into the study, with a mean age of 38.7 ± 14.4 years and a median of 41 years (range, 2 - 79); most (33.3%) were aged 40 - 49 years, and most were female (71.3%), for a sex ratio of 0.4.

3.1. Characteristics of Patients

Immunological failure was seen in 20.2% and virological failure in 44.5% of patients. Anaemia was observed in 28.0% of patients (Table 1).

3.2. Biological Parameters of Patients

Patients with immunological failure had lower mean values for haemoglobin, haematocrit, mean blood count, leukocytes, polynuclear eosinophils and basophils and lymphocytes than those with immunological success but higher values for creatinine, ALAT and ASAT (Table 2).

Biological Anomalies

The biological anomalies observed are shown in Table 4 and Table 5.

Patients with immunological success were more likely to have anaemia (65.4% of females and 59.3% of males), leukopenia (66.6%), eosinophilia (85.8%), lymphopenia (56.3%), thrombopenia (65.0%), microcytosis (69.7%), hypochromia (72.0%) and abnormal ASAT (74.8%). Of patients with a high viral load, 36.9% had anaemia, 51.6% had leukopenia, 46.0% had neutropenia, and 52.6% had lymphopenia. Blood creatinine was abnormal in 37.4% of patients with a high viral load, and abnormal ALAT and ASAT were found in 36.4% and 41.2% of these patients (Table 5).

## 4. Discussion

Our finding of a sex ratio of 0.4 and a median age of 41 years are similar to those of Mouala et al. [13] , who also found a sex ratio of 0.4 and a median age of 32.5 years among HIV-positive patients in Bangui, and of Loua et al. [16] , who reported a sex ratio of 0.5 and a median age of 40 years in a study in Conakry, Guinea. Mouhari-Touré et al. [17] reported a predominance of women (68.6%) in a study in Togo. These findings indicate that HIV infection is a problem mainly among young, sexually active women. UNAIDS reported in 2016 that women represented 56% of all people living with HIV in West and central Africa [1] .

In our study, 79.8% of patients had a CD4 count ≥ 200/mm3, and 44.5% had a viral load of <1000 copies/mL. Lozès et al. [18] found that, after 12 months of treatment, 83.0% of patients had an undetectable viral load and 86.0% had recovered their immunocompetence. Our immunological result is therefore similar, but a high viral load persisted.

Haematological anomalies in patients on ART are the result of both immunodeficiency and dysregulation of the immune system. Anaemia was observed in 28.0% of patients in our study. This was the principal haematological anomaly found in other studies of people living with HIV: in 75.8% in Bangui [16] , 95.2% in Zimbabwe [7] , 54.5% in Conakry [17] and 13.8% in Togo [19] . We found lower mean values for haemoglobin, haematocrit, mean cell count, leukocytes, polynuclear eosinophils and basophils and lymphocytes but higher blood creatinine, ALAT and ASAT values among patients with a low CD4 count. Immunological failure may be due to complications of opportunistic bacterial, viral, parasitic or fungal infections or to the direct effect of the virus on certain haematopoietic progenitors, giving rise to anomalies in all cell lines [20] . Multiple ART and their secondary effects on patients' organ systems may be responsible for renal and hepatic lesions [21] .

Patients with virological failure had lower mean values for erythrocytes, haemoglobin and mean blood count but a higher mean value for ASAT. The mean haemoglobin concentration was 12.4 g/dL for patients with a low viral load and 11.6 g/dL for those with virological failure. Nacoulma et al. [22] found a haemoglobin level of 12.2 g/dL in a study in Burkina Faso. Such anomalies are due to the various mechanisms of HIV infection, which lead to lesions in different cells and organs. Immunological and virological failure evolves to therapeutic failure when patients are exposed to drugs that are toxic to cells.

Patients with a high CD4 cell count were more likely to have anaemia, leukopenia, eosinophilia, lymphopenia, thrombopenia, microcytosis, hypochromia and abnormal

ASAT. These anomalies may be due to various inflammatory mechanisms of HIV infection and secondary effects of ART and of treatments for opportunistic infections. Beuzit et al. [8] found rates of 74% for anaemia, 20% for neutropenia and 15% for thrombopenia in central Africa, and Erhabor et al. [23] found rates of 80%, 24% and 10%, respectively, in Nigeria. The high frequency of anaemia in these two studies was measured before initiation of treatment.

Creatinine was abnormal in 61.0% of our patients, and the transaminases ALAT and ASAT were abnormal in 57.0% and 66.9% of patients, respectively. These results corroborate those of Mouhari-Touré et al. in Togo, who found elevated ASAT in 55.9% of patients and elevated ALAT in 29.8%, with a mean creatinine level of 9.6 ± 5 mg/L. HIV infection, its treatment and the associated opportunistic infections are all chronic conditions, with harmful effects on stromal, haematopoietic, hepatic and renal cells and the organism's defence mechanisms.

Patients with a high viral load were more likely to have leukopenia, leukocytosis, polynuclear neutrophilia, lymphocytosis, monocytosis, thrombocytosis and hypochromia and less likely to have anaemia and abnormal blood creatinine, ALAT and ASAT. These biological abnormalities are due to the immunodeficiency induced by HIV and also to complications of treatment, opportunistic infections and side-effects of ART.

## 5. Conclusions

We found immunological failure in 20.2% of patients and virological failure in 44.5%. The main haematological anomalies observed were anaemia, leukopenia, neutropenia and lymphopenia. Blood creatinine was abnormal in 61% of patients, and liver transaminase levels were high. Biological profiling is essential for the diagnosis of therapeutic failure and for the prognosis of HIV infection. The anomalies observed in this study mainly affected the haematopoietic system, the liver and the kidneys. As other organs and systems may also be affected, people living with HIV should undergo periodic multidisciplinary clinical and biological follow-up in order to improve their management.

## 6. Strengths and Limitations

Since the recent introduction of HIV-1 viral load measurement in CAR, this study is the first to describe the complete biological profile of Central-African patients infected with HIV. The virological, immunological and haematological parameters were studied as well as liver and renal functions. Anemia was the most frequent abnormality described, as reported in other studies [7] [8] [20] [21] [22] . The limitation of the study concerns the poor access to laboratory facilities in the provinces. Since the Pasteur Institute is located in Bangui, most of the patients included come from the capital city. We recommend national policies together with International support will be able to implement the follow-up of HIV infected patients in the provinces.

Conflicts of Interest

The authors declare no conflicts of interest.

Cite this paper

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